Palliative Care Guidelines For Primary Health Care

ADDIS ABABA CITY ADMINISTRATION HEALTH BUREAU
MEDICAL SERVICE DIRECTORATE, 2016 E.C

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List of Abbreviations

AIDS.....**Acquired Immunodeficiency Syndrome**
ATC.....**Around-the-clock**
Bid.....**Twelve hourly**
FMOH.....**Federal Ministry of Health**
HCW.....**Health care worker**
HIV.....**Human Immunodeficiency Virus**
ICP.....**Intracranial Pressure**
i.m.....**Intramuscular**
i.v.....**Intravenous**
NSAID.....**Non-steroidal anti-inflammatory drug**
Po.....**Oral medication**
PLWHA.....**People Living with HIV/AIDS**
PRN.....**As needed**
Qid.....**Six hourly**
SSRIs.....**Selective serotonin reuptake inhibitors (SSRIs)**
Tid.....**Every Eight hourly**
FHT.....**Family Health Team**
PC.....**Palliative Care**
EHAQ.....**Ethiopian Hospital Alliance for Quality.**
EPAQ.....**Ethiopian Primary Health Care Alliance for Quality**
GERD.....**Gastro -Oesophageal Reflux**
UTI.....**Urinary Tract Infection**
WHO.....**World Health Organization**

Foreword

Addis Ababa is not only the heart of Ethiopia but also a diverse community with a rich tapestry of cultures, traditions, and healthcare challenges. It is within this mosaic that palliative care takes on an even deeper significance, transcending medical treatment to encompass cultural sensitivity, empathy, and holistic support. Palliative care has not been part of the Primary health care services until recently.

Despite the need for an improvement in our healthcare provision for end-of-life care as well as care for patients and families of patients who deal with serious life-limiting and terminal illnesses, palliative care's importance has gained major attention in recent years globally and nationally as well as regionally.

The epidemiologic and demographic shift of communicable, non-communicable, and emerging and remerging diseases as well as road traffic accident incidence has increased. With the number of people suffering from life-threatening illnesses rising to an alarming rate, this shows the demand for urgent need to incorporate palliative care services with the regular services in our health care setup starting from the primary level of care.

Palliative care plays a crucial role in primary care units. This manual covers a wide range of topics, focusing on improving the quality of life for patients with serious illnesses, providing symptom management, psychosocial support, pain management, ethical considerations, and communication strategies and guidance for patients and their families as well.

Thank you for your dedication to improving healthcare services in our city. Together, we can make a significant difference in the lives of patients and their families during their most challenging times.

With heartfelt gratitude to all who contributed to this guideline,

Yohannes Challa (MD, General Surgeon)
Bureau Head

Message from Vice Bureau Head

Integrating palliative care services into primary care units is an important step in providing comprehensive and holistic healthcare to patients with life-limiting illnesses. By doing so, we can ensure that patients receive specialized and personalized care throughout the course of their illness. Here are some reasons why integrating palliative care services into primary care units are beneficial:

Continuity of care: Integrating palliative care into primary care allows for seamless coordination between various healthcare providers involved in a patient's care. This improves communication and ensures that patients receive consistent and coordinated support.

Early identification: Primary care providers are often the first point of contact for patients. By integrating palliative care services, healthcare providers can identify patients who may benefit from palliative care early on in their illness trajectory. This helps in providing timely support and alleviating symptoms.

Comprehensive management: Palliative care focuses on managing pain and other distressing symptoms, as well as addressing emotional, psychological, and spiritual needs. By integrating these services into primary care, patients can benefit from a comprehensive approach that addresses all aspects of their care.

Patient-centered care: Palliative care is grounded in patient-centered principles, focusing on the individualized needs and goals of the patient. By integrating these services into primary care, patients can receive care that aligns with their preferences and values, promoting better quality of life.

Cost-effectiveness: Integrating palliative care into primary care can help reduce healthcare costs by preventing unnecessary hospitalizations, emergency department visits, and repetitive diagnostic tests. It also helps in optimizing resource utilization by providing care in the most appropriate setting.

To integrate palliative care services into primary care units, it is essential to establish clear referral pathways, educate primary care providers about palliative care principles, and provide training to enhance their skills in managing palliative care needs. Collaboration with specialist palliative care teams is crucial to ensure a multi-disciplinary approach and ongoing support.

Additionally, it is vital to create awareness among patients and their families about the benefits of palliative care and address any misconceptions or fears they may have. This can be done through community education programs and by providing informational materials.

By integrating palliative care services into primary care units, we can improve the overall quality of care and support provided to patients with life-limiting illnesses, ensuring their physical, emotional, and spiritual well-being.

Mulugeta Endale (MD)
Vice Bureau Head

Message from Medical Service Director

In the journey of healthcare, there exist critical moments when our compassion, knowledge, and commitment shine most brightly. Palliative care represents one of these vital touch points, where we provide comfort, relief, and dignity to individuals facing life-limiting illnesses and their families.

Palliative care focuses on improving the quality of life for patients with serious illnesses, managing their symptoms, and providing psychosocial and emotional support to both patients and their families. Integrating palliative care into primary care settings ensures that patients have access to these services early on in their illness, leading to better outcomes and improved client satisfaction.

Elaborating some points on the importance of palliative care in the primary care setting:-

Symptom management: palliative care experts can help address and manage symptoms such as pain, nausea, fatigue, and shortness of breath. They work closely with primary care providers to develop personalized care plans that enhance comfort and relieve distressing symptoms.

Emotional and Psychosocial support: palliative care teams offer emotional support to patients and their families, helping them cope with the challenges of serious illness. They provide counseling, facilitate important conversations about goals of care, and assist in decision-making processes.

Care coordination: Palliative care providers collaborate with primary care teams to ensure seamless coordination of care across different healthcare settings. They help navigate complex medical systems, provide education to patients and families, and ensure continuity of care.

Advance care planning: Palliative care professionals assist patients in discussing and documenting their healthcare preferences, including end-of-life care choices. They can help facilitate these conversations and ensure that patient's wishes are respected and followed.

Family support: Palliative care teams also provide support to family caregivers who may experience significant emotional and physical strain while caring for a seriously ill loved one. They offer education, respite care options, and guidance on managing caregiver burnout. By integrating palliative care into primary care units, patients can receive comprehensive, patient-centered care that addresses not only their physical symptoms but also their emotional, social, and spiritual well-being.

In the area of primary healthcare, the provision of palliative care requires a unique mix of medical expertise, compassion, and sensitivity. As our healthcare setting evolves, we must equip our primary healthcare units with the knowledge and tools necessary to offer dignified and holistic care to patients and their families during their most vulnerable times.

The bureau is taking a major leap towards launching palliative care services in our primary health care units marking a significant step forward in delivering comprehensive, patient-centric care in Addis Ababa. We firmly believe that by offering palliative care services at the primary health care level, we can make a positive impact on the lives of many individuals and families facing challenging health circumstances.

This guideline is a comprehensive resource tailored to the unique context of Addis Ababa's primary care settings, aiming to equip health care professionals with the knowledge and tools necessary to deliver exceptional palliative care. By integrating the principles outlined in this guideline into your practice, you can make a significant difference in the lives of patients and their families during their most challenging times.

Acknowledging its pivotal significance, this guideline has been crafted collaboratively by a dedicated team of medical professionals, experts, and caregivers who are deeply committed to improving the lives of patients in their journey through illness.

As you look deeper into this guideline, I encourage you to embrace its principles and insights. Let it serve as a guiding light as you navigate the challenging but rewarding journey of providing palliative care within the primary healthcare setting.

Together, we can make a meaningful difference in the lives of patients and their families.

Melkamu Tiruneh (BSC, MPH, MSC)
Medical Service Director

Acknowledgments

We would like to express our heartfelt appreciation and gratitude to all those who contributed their time, expertise, and unwavering support in bringing this essential project to fruition. The creation of these guidelines would not have been possible without the collective efforts and dedication of numerous individuals and groups.

First and foremost, we extend our sincerest gratitude to the leadership of the AACHAB, Medical service directorate specialty team for recognizing the importance of palliative care and providing us with the opportunity and resources to undertake this significant endeavor.

Ultimately, these Palliative Care Guidelines for primary health care stand as a testament to the power of collaboration, compassion, and the shared goal of improving the lives of those living with serious illnesses. It is with profound gratitude that we acknowledge the Global Fund for their financial support to give a basic training of palliative care for health care professionals at primary health care unit and every individual as well as entity that played a part in this endeavor.

Thank you for your unwavering commitment to palliative care and your belief in the importance of providing comprehensive, compassionate, and dignified care to patients and their families. Your contributions will undoubtedly make a difference in the lives of many and leave a lasting impact on the field of palliative care.

We would like to thank the Palliative Care Guideline Technical Working Group, composed of experienced healthcare professionals. Their commitment to excellence and their passion for improving the quality of life for patients facing serious illness were the driving forces behind the development of these comprehensive guidelines.

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Users Guide: purpose and intended users

The Guideline covers a range of proven palliative care approaches, including symptom management, pain management, psych-social and spiritual management approaches, which can be applied in the primary health care setting. The choice of drugs was made based on the current policies and guidelines pertaining to procurement and use of drugs at the various levels of health care delivery. Due consideration was made to suggest improvements when the current policies and guidelines constrain effective management of palliative care patients.

This Guideline is developed to assist the primary health care professionals in making decisions about palliative care service. It provides useful recommendations that are supported by the current literature and synthesis of expert opinions. However, this guideline is not intended to be a rigid procedure. Its use guarantees no specific outcome. The guideline is subject to revisions as warranted by medical advances. Thus, decisions to adopt any particular recommendation must be made by the practitioner in light of circumstances presented by individual patients. The guideline covers the gaps seen in palliative care in existing guidelines and aligned with the existing standard treatment guideline.

The primary targets of this guideline are health care providers at primary health care delivery but it could also be a useful reference for health managers and policy makers. It is important for health workers to be aware of the following facts in managing palliative care patients:

- Prioritized routine clinical services then initiate palliative care service after patient diagnosis is confirmed.
- During giving the care the set-up and available multi-disciplinary team (refer MDT) should be fulfilled.
- Asses the total pain of the patient based on the standard assessment tool
- Assess the risks and benefits of the drugs to be used
  Consider non-pharmacologic therapies to maximize total pain relief while decreasing side effects
- During managing palliative care patients, the multidisciplinary team must assess the patient family with better communication skill and empathy
- Use less invasive, less costly therapies before resorting to more invasive and costly therapies.

Rationale behind Preparing this Guideline

The second version of the Health Sector Transformation Plan (HSTP) endorsed by Addis Ababa Health Bureau has strategized accelerated progress towards Universal Health Coverage in the next five years. The implementation of palliative care in the primary health care setting is part of this effort. Palliative care is recognized as an essential service in the package for the Universal Health Coverage (UHC), which mandates that everyone has access to the primitive, preventive, curative, rehabilitative and palliative health services they need.

To ensure access for palliative care in the community it should be integrated into the primary healthcare level. Primary healthcare facilities are not prepared to provide

palliative care services to individuals in need of such care. “Access is least likely in the community where most of the patients are and wish to remain. Thus, millions of vulnerable people are being denied their right to the highest attainable standard of well-being. Most suffering due to serious or life-threatening health problems can be relieved with inexpensive, safe and effective medicines and equipment prescribed by any physician, clinical officer or assistant doctor with basic palliative care training” (WHO). Health professionals are expected to provide palliative care as a core part of their practices in primary health care. The guideline, therefore will help to offer direction and guidance for putting palliative care services into practice in a community and facility context. To this end, in response to chronic, life-threatening disorders and other non-communicable diseases, the development of the palliative care guidelines for primary health care was justified.

Figure:- Illustrates the source of "Total Pain" for palliative patients according to WHO.

Objectives of the Guideline

- To initiate palliative care services in the primary health care setting
- To standardize palliative care services in the primary health care setting
- To integrate palliative care into the routine clinical services
- To strengthen referral linkage and networking of palliative care services
- To promote access to quality palliative care services

Multi-disciplinary Team and Their Role

The ‘family health team’ is a team formed to provide family healthcare at the primary level, health center. The team is organized from the health center staff in 3-5 teams, each consisting of a medical doctor or health officer or nurse with a bachelor’s degree to serve as a lead: clinical nurses, and urban health extension professional and social worker. The teams provide targeted services to priority populations through home visit or outreach sites and to make referrals for further care at health centers. Adult populations with chronic problems and non-communicable disease who belong to the lowest income category are targeted as priority to access care by the team. Urban

health extension professionals with support from their supervisors, will identify populations that need to be visited by the family health team and decide with the team leader. Based on the advance arrangement/preparation, the team will visit the identified families with all the necessary supplies to provide services at the household level. The team gives health education for family members and makes referrals if further care is needed at a health center or higher-level facility.

Ideally the palliative care interdisciplinary team includes a doctor, nurse, a social worker, a psychologist, spiritual/religious leader, all trained in palliative care. Each professional knows the basic assessment and management principles of palliative care, addresses symptoms in a holistic manner. They learn the duty of one another and consult among the members for complicated issues. For example, a nurse could do some counseling with the family but might need the assistance of a psychologist in managing severe depression. Considering current situation in Ethiopia, clinical nurses, and urban health extension professional and health officers after training in palliative care, will have the following roles:

- Health extension professionals and the nurse undertake the clinical assessment through the clerking sheet / encounter forms. They would assess palliative care needs using a screening form which comprehensively identifies the physical, psychological, social needs of the patient.
- Health officers/MD could prescribe stage 1 and 2 medications on the WHO pain scale ladder. Health professionals can alternate roles for e.g. the public health professional can take the role of occupational therapist, social worker or religious advisor according to their skills and interest
- The social worker will assess the socio-economic status of patients in terms of managing finances and linking with social support/ financial aid...etc

Chapter 1
Background

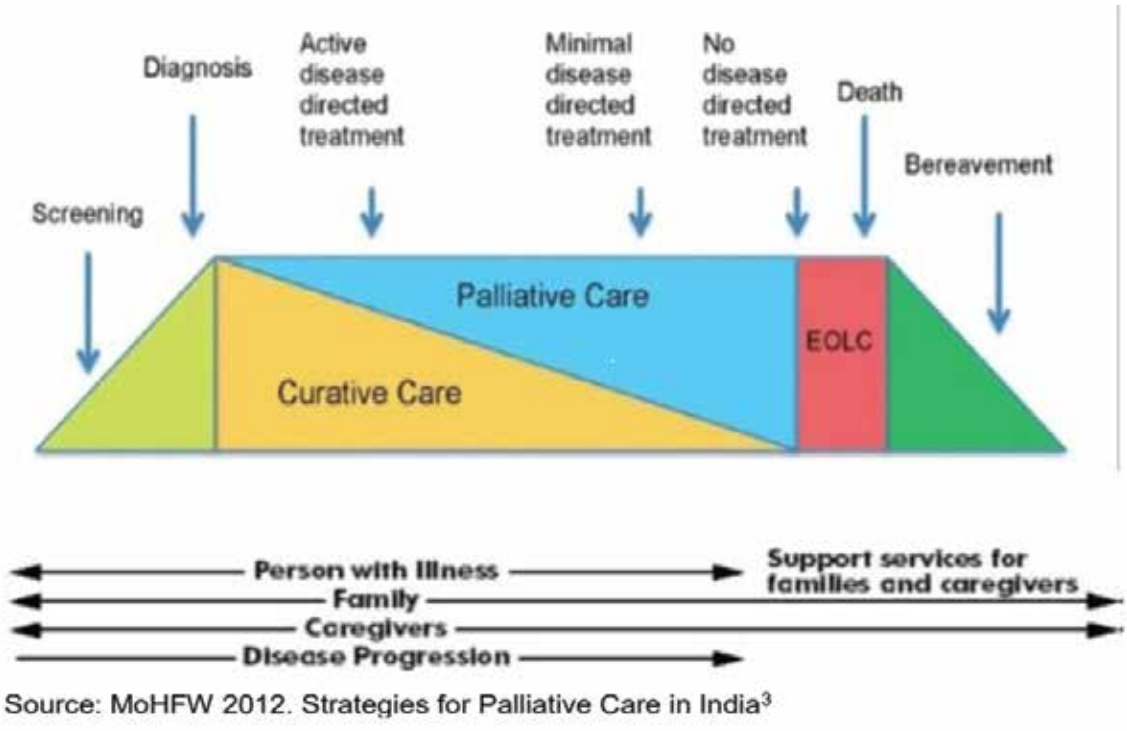
More than 80% of all deaths occur after a certain period of debility. The conditions leading to these deaths and debility could be Non-Communicable Diseases (NCDs), notably cancer and also diabetes, cardiovascular diseases (non-acute), chronic respiratory diseases, renal failure, neuropsychiatric illnesses, Alzheimer's disease or other age-related issues, certain chronic infections like HIV and drug resistant tuberculosis and other chronic incurable illnesses and conditions. The health care system traditionally focuses more on acute illnesses where the people affected mostly get back to their normal lives. The chronically and incurably ill people need regular supportive care but the system is not well equipped-both in terms of skills and facilities required- to provide this support. So these people are sent home saying 'we cannot do anything more for him/her'. The society also feels helpless as they do not know how to address the suffering of their fellow beings sent back from health institutions. Palliative care tries to address these issues.

Worldwide, around 40 million people need palliative care each year and more than three quarters of them live in low- and middle-income countries. Only 14% of them have access to palliative care. 83% of the world's population has poor access to pain relieving opioid medications. 69% of the people needing palliative care are above sixty years of age and 6% are children. More than two thirds of the countries in the world either have no palliative care services or isolated service provision.

Definition of Palliative Care

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, diagnosis and treatment of pain including physical, psychological, social and spiritual problems.
Palliative care:

- Provides relief from pain and other distressing symptoms;
- Supports 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.



Source: MoHFW 2012. Strategies for Palliative Care in India[3]

Figure 1.1 illustrates a "continuum of care" for cancer, HIV/AIDS, and other life-limiting diseases.

Who benefits from palliative care?

Palliative care treats people suffering from serious and chronic illnesses including cancer, cardiac disease such as Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), kidney failure, Alzheimer's, HIV/AIDS and Amyotrophic Lateral Sclerosis (ALS). Palliative care relieves the symptoms of these diseases, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps one gain the strength to carry on with daily life. It improves the patients' ability to tolerate medical treatments. And it helps patients' have more control over patients' care by better understanding your choices for treatment options.

Chapter 2
Physical Pain Assessment and Management

2.1 Definition of Pain

Pain is a complex phenomenon, and the experience of pain is unique for each individual. It can be defined as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP).

Pain is a subjective experience. The experience varies from person to person and from time to time. Pain is whatever the experiencing person says it is, existing wherever he says it does **"Total Pain"** refers to the global nature of pain perception not only as a physical ailment but that it has psychological, spiritual and social consequences. Such pain requires holistic approaches during interventions.

2.2 Classification of Pain

2.2.1 Based on Duration

Acute pain - has a well-defined onset, generally associated with subjective and objective physical signs

- Definite onset with limited and predictable duration
- Clinical signs of sympathetic over-activity: tachycardia, pallor, hypertension, sweating, grimacing, crying, anxious, pupillary dilation
- It usually responds to analgesic drug therapy and treatment of its underlying cause.

Chronic pain - persists over weeks or months and may be associated with significant changes in lifestyle, functional ability and personality.

- Gradual or vague onset
- Continues and may become progressively more severe
- Patient may appear depressed and withdrawn
- Usually no signs of sympathetic over-activity

2.2.2 Based on Mechanism

Nociceptive pain - pain occurring with an identified lesion causing tissue damage that leads to stimulation of nociceptors in somatic and visceral structures. Nociceptive pain may be further classified into somatic and visceral types. Somatic pain relates to damage to structures such as bone and muscle, while visceral pain relates to a lesion in, or compression of a hollow viscus or solid organ.

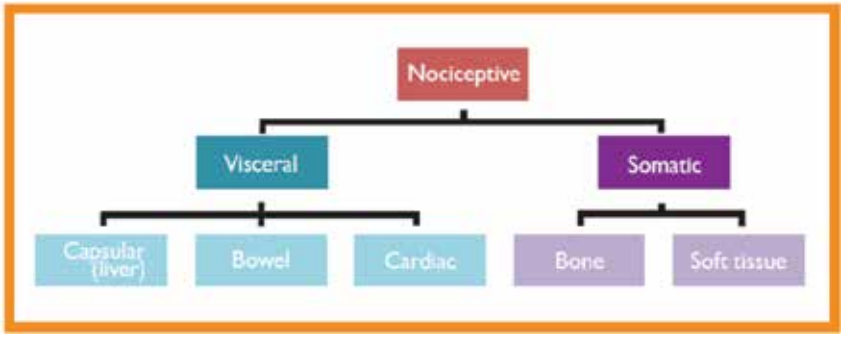


Figure: - illustrate common classification methods of nociceptive pain

Neuropathic pain results from and is sustained by nerve damage in either the central or peripheral nervous system. Neuropathic pain may be constant or intermittent, and may be spontaneous or provoked. Typically, it follows a dermatomal distribution and can be described as shooting, stabbing, burning, pins and needles, or like electric shocks.

2.2.3 Based on Situation

Breakthrough pain:- is defined as, "a transient exacerbation of pain that occurs either spontaneously, or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain".

Incident pain:- is either voluntary or involuntary, and has an identifiable precipitant e.g., dressing changes or movement.

End of dose failure:- Pain occurring towards the end of the expected duration of action of an opioid (i.e. 8-10h after giving a 12h preparation). It is NOT considered as break-through pain; the background opioid dose may need adjusting.

2.3 Pain Assessment

Accurate assessment of pain is essential to plan appropriate interventions or treatments. Uncontrolled pain limits a person's ability to self-care, affects their response to illness and reduces their quality of life. Pain assessment should be holistic, and can be considered under the following categories: Physical, Psychological, Social and Spiritual.

It is imperative that patients' anxieties and frequent misconceptions related to the above factors are explored. To ignore psychological and spiritual aspects of care may often be the reason for seemingly intractable pain.

A

ONSET	When did it begin? How long does it last? How often does it occur?
PROVOKING/ PALLIATING	What brings it on? What makes it better? What makes it worse?
QUALITY	What does it feel like? Can you describe it?
REGION/RADIATION	Where is it? Does it spread anywhere?
SEVERITY	What is the intensity of the pain? (On a scale of 0 to 10 with 0 being none and 10 being the worst possible) Right now? At best? At worst? On average?
TIMING/TREATMENT	Is the pain constant? Does it come and go? Is it worse at any particular time? What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments?
UNDERSTANDING/ IMPACT ON YOU	What do you believe is causing the pain? Are there any other symptoms with this pain? How is this pain impacting you and your family?
VALUES	What is your goal for this pain? What is your comfort goal or acceptable level for this pain? (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this pain that is important to you or your family? Is there anything else you would like to say about your pain that has not been discussed or asked?

Table 1: Pain assessment using Acronym O, P, Q, R, S, T, U, and V

In addition to the table you can consider the following: -

1. The Numeric Pain Rating Scale
2. The Hand scale
3. The Wong-Baker scale (also known as the FACES scale)
4. The FLACC scale
5. PAINAD (pain assessment for advance dementia)

1. Numeric Pain Rating Scale

The health worker asks the patient to rate their pain intensity on a numerical scale that ranges from (indicating 'no pain') to 10 (indicating the 'worst possible pain').

Procedures

A) Explain to the patient about what you are going to do (eg. 'I want to assess your pain level to help us properly manage the pain'
B) Ask the patient 'please rate your pain in a scale from zero to 10 (0 = no pain and 10 = worst Possible pain). You can use a scale like below
C) Numeric Pain Rating Scale Record the patient scored pain level on the nec-essary form to make treatment decisions, follow-up, and compare between examinations

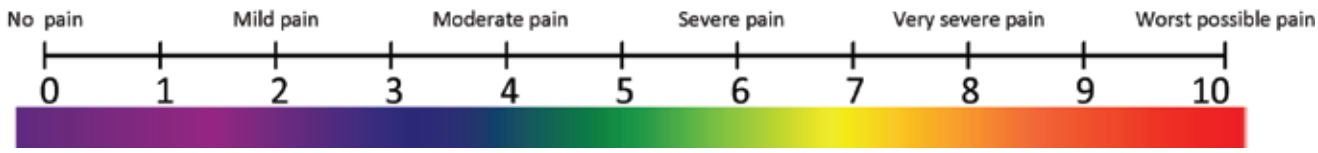


Figure 1: Numeric Pain Rating Scale

2.The Hand Scale

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

A) Explain to the patient about what you are going to do (e.g. 'I want to assess your pain level that will help us properly manage your pain'
B) Show your hands to the patient and ask 'please rate your pain level. You should show your hands like below or use the drawing use a scale
C) Multiply the result by two to score the pain to 0 to 10 and record on the neces-sary forms (if the patient reports hurts whole lot mean four figures the result will be recorded as 4*2= 8 on the routine observation form).

- You will learn about pain assessment under three and neonate patients in respective chapter Pain In pediatrics

2.The Wong-Baker scale (also known as the FACES scale) - see Palliative care in pediatrics section

3.The FLACC scale ------ see Palliative care in pediatrics section

4.PAINAD (Pain Assessment for Advanced Dementia patients)

Pain assessment has to consider other domains of pain such as psycho-social and spiritual aspects.

2.4 Pain Management

2.4.1 Principles of pain management

- By the mouth – ideally the oral route should be used first line.
- By the clock – regular analgesia ensures blood levels are maintained and reduces the need for PRN medication.
- By the ladder: analgesia should be increased in response to the degree of pain according to the WHO analgesic ladder.
- Individual dose titration: Comprehensive, individualized and holistic assessment and treatment planning, including regular review and reassessment with involvement of the wider multi-professional team as appropriate.
- Patients should be encouraged to take an active role in their pain management.
- Morphine is currently considered to be the strong opioid of choice.

2.4.2 The WHO Analgesic Ladder

The WHO analgesic ladder has 3-step ladder for adults and 2-step ladder for children (Updated in 2012). It created a framework for pharmacological management of pain. 80-90% of patients are effectively treated using the WHO 3-step approach.

Figure 3: The analgesic ladder for pain management

Using the WHO ladder for adults

- Mild pain - start with a non-opioid, for example with regular paracetamol or non-steroidal anti-inflammatory drug (NSAID), then move up steps if pain remains uncontrolled.
- Moderate Pain - start with a weak opioid.
- Severe Pain - start with a strong opioid.
- Adjuvants can be used at any step of the ladder

Weak Pain
Non-Opioids
Paracetamol

- Centrally acting non-opioid analgesic with antipyretic properties.
- Metabolized by the liver therefore caution or avoidance in liver failure or compromise
- Adult dose: 500mg-1g by mouth every 6 hours; maximum daily dose 4g
- Note: Hepatotoxicity can occur if more than the maximum dose is given per day
- Paracetamol can be combined with an NSAID

NSAIDS:- including COX-1 and selective COX-2 inhibitors reduce the inflammatory sensitization of nerves by inhibiting prostaglandin synthesis via the COX pathways (by blocking a specific group of enzymes called cyclo-oxygenase enzymes).eg, diclofenac and Ibuprofen.

- NSAIDs are useful in managing pain from bones and joints.

Ibuprofen

- Adult dose: 400mg by mouth every 6-8 hours; maximum daily dose 1.2g
- Give with food and avoid in asthmatic patients
- The maximum dosing limit should be lowered in patients with liver impairment

Diclofenac Adult dose: 50mg by mouth every 8 hours; maximum daily dose 150mg

- Give with food and avoid in asthmatic patients

Side-effects of NSAIDs

Gastric - Dyspeptic symptoms and gastro-intestinal (GI) ulceration are frequently associated with NSAIDs.

- Celecoxib is associated with the lowest risk of GI complications
- Diclofenac, low dose Ibuprofen and naproxen have intermediate risk
- Ketoprofen and piroxicam are associated with a relatively high risk

Cautions with NSAIDs: they can cause serious side effects, particularly after using for more than 7-10 days.

Moderate Pain
Opioids

Opioids are morphine-like drugs. Opioids can be categorized into two groups.

- Weak opioids such as Tramadol, and codeine
- Strong opioids such as morphine are commonly used as strong opioids.

Tramadol

- Adult dose: 50-100 mg by mouth every 8 and 12 hours
- Start with a regular dose and increase if no response (dose limit: 400mg/day)
- Use with caution in epileptic cases, especially if patient is taking other drugs that lower the seizure threshold
- To obtain an equivalent morphine dose, divide the dose of Tramadol by 10.
- May be preferable to other opioids in the management of pain due to pancreatitis and neuropathic pain
- Consider patient condition for laxative to avoid constipation
- This drug shouldn't be used in children

Codeine - It is a weak opioid used for moderate pain. The analgesic effect of codeine is due to codeine being converted to morphine in the body. Maximum onset of action is 30-60 mts.

- Adult dose: 30-60 mg by mouth every 4 hours; maximum daily dose 240 mg
- If pain relief is not achieved with 240 mg/day, move to strong opioid
- Can be combined with Step 1 analgesic
- Give laxative to avoid constipation unless patient has diarrhea
- It is much less potent than morphine
- It has analgesic, antitussive properties;
- It has ceiling effect beyond which increasing dose will be of no benefit but with serious side effects
- 1/10th the potency of oral morphine
- Do not use codeine for children

Low-dose morphine

- Using low-dose morphine in step 2 is recommended because it is associated with fewer side effects compared to other weak opioids

Severe Pain
Strong Opioids
Morphine

- When used correctly, patients don't become dependent or addicted, tolerance is uncommon, and respiratory depression doesn't usually occur.
- A laxative –routinely (Unless there is a strong reason like-ileostomy)
- Patients should be informed (warned) about the possibility of initial drowsiness.

Route	Bio-availability	Plasma peak time	Half life	Duration
Oral	35%	1-6 hrs	1.5 hr	3-6 hrs
Rectal	25%	30-60 min	1.5 hr	
IV	100%	5-10 min		
IM	100%	5-10 in		

Table 2: Morphine Administration

Morphine side-effects

Opioid induced Constipation

- Prescribe regular laxative for all patients (bisacodyl 5-15 mg po/day)
- Tell patients that laxatives take time to work, how to titrate & importance of adherence

Drowsiness

- May occur at initiation and following an increase or after a PRN dose
- Usually, self-limiting
- May affect their ability to drive

Nausea

- Consider PRN or regular ant-iemetic
- Usually, self-limiting

Side effects of opioids are rare when they are used in appropriate doses

Signs include

- Drowsiness that does not improve
- Confusion
- Hallucinations
- Myoclonus (abrupt spasms or muscle twitching)
- Respiratory depression (slow breathing)
- Pinpoint pupils

Opioid Side effect Management

If you are concerned that a patient is experiencing side effects, reduce the dose by 50% and consider giving parenteral fluids to increase excretion.

In severe cases, stop the opioid and give Naloxone, an opioid antagonist. Naloxone is rarely used and should be used with caution as it will precipitate pain crisis:

A. Stop the opioid
B. Oxygen via face mask
C. IV naloxone 100-200 micrograms (1.5-3mcg/kg) as a slow bolus
D. If response inadequate, give further 100micrograms every 2 minutes
E. Carefully monitor vital observations whilst aiming to maintain/restore

pain relief (monitor for signs of withdrawal as well as overdose)
If signs recur, consider further naloxone boluses/infusion and seek advice.
Indication for naloxone

- RR< 8/min
- RR< 12/min, difficult to rouse, cyanosis
- RR < 12/min difficult to rouse, sao2<90%

- To give Haloperidol 1.5-5 mg at night may help with any hallucinations or confusion. Be sure to rule out other causes (such as urinary tract infection, hypoxia, or side effect of another medication)

Tolerance is loss of efficiency of medication whereby a higher dose is required to bring about the effects achieved previously like e.g. drowsiness, nausea. This is the earliest stage.
Dependence on physical or psychological symptoms that come about when the medication is suddenly stopped.

- This followed by withdrawal symptoms such as increased salivation, lacrimation, rhinorrhea, sweating, abdominal cramps, diarrhea, insomnia.
- This can be managed either by restarting morphine or prevented by tapering medication slowly
- Reduce daily dose by 25% each day

According to the World Health Organization: A systematic review of research papers concludes that only 0.43% of patients with no previous history of substance abuse treated with morphine analgesics to relieve pain abused their medication and only 0.05% developed dependence syndrome.

Addiction is difficulties in controlling substance use, onset, termination, or levels of use, described by one or more of the following

- Losing control over how much morphine you are taking
- Obsessing over where your next dose of morphine is coming from
- Continuing to use morphine despite experiencing unpleasant side effects
- Seeing relationships suffer and losing interest in other activities
- Experiencing distinct cravings for morphine
- Trying, but failing, to reduce the amount taken
- Your interpersonal relationships are suffering and you have lost interest in activities you used to enjoy
- Feelings of depression/anxiety and being 'trapped'
- Feelings of shame and guilt related to your morphine use
- Experiencing distinct cravings for morphine
- Taking increasing amounts of morphine as your tolerance increases
- Using morphine purely to get high (ie continuing to use morphine when the pain related condition has been resolved or taking morphine that has not been prescribed for you)
- Lying, cheating, stealing or manipulating in order to get morphine
- Experiencing morphine withdrawal symptoms
- Hiding the true extent of your morphine use from others
- Mixing morphine with alcohol or other drugs for greater effect

Management Principle of morphine addiction

- Addiction counseling
- Mutual help group
- Pharmacotherapy
- Psychotherapy
- Subsequent continuing care.
- Please refer the patient to psychiatrist for the last three treatment recommendations and for further work up

Dose Adjustment

- Adult starting dose of Morphine for opioid naive: 2.5–5 mg by mouth every 4 hours depending on age, previous use of opiates, etc.
- Patients changing from regular administration of a Step 2 opioid: 10mg by mouth every 4 hours.
- If the patient has experienced weight loss from sickness or has not progressed onto Step 2 analgesics: 5mg by mouth every 4 hours.
- Frail or elderly patients: 2.5mg by mouth every 6 to 8 hours due to the likelihood of impaired renal function

Morphine is poorly responsive to

A.Raised intracranial pressure
B.Bone metastasis (and some soft tissue pains)
C.Neuropathic (i.e., nerve compression and nerve injury).
D.Under dosing (dose too small or given only as needed)
E.Ignoring psychological, social and spiritual factors.

2.4.3 Adjuvant or Co-analgesia

Adjuvant analgesics, which are also referred to as co-analgesics, are medicines that are not primarily used for analgesia. These are medicines that are administered alone or with NSAIDs and opioids that may:

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

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

Anti-Depressant

Amitriptyline

- Adults: 10-75 mg or 0.5-2 mg/kg at night then increase slowly as needed
- Commonly start at 12.5mg at night and then increase to twice per day as needed
- Response should be evident within 5 days. If no effect after 1 week, stop the drug

Side-effects include dry mouth and drowsiness
Use with caution in the elderly because it may increase falls and with cardiac disease because it may cause orthostatic hypertension

Anticonvulsants

- Clonazepam- Adults: 0.5mg to 2mg once a day
- Carbamazepine -Adults: start at 100mg twice a day and can be increased up to 800 mg twice a day
- Sodium valproate-Adults: 200 mg - 1.2g once a day
- Gabapentin-Adults: start with 300mg at bedtime and titrate up every 2 or 3 days (300 mg twice per day, then three times per day) until effective or side effects occur. Usual effective dose is 300-600 mg three times a day (maximum dose 1200 mg three times per day) Decrease dose in patients with renal insufficiency.

Steroids

- Dexamethasone- Adults: 2–4 mg per day for most situations. For raised intracranial pressure, start at 24 mg per day and reduce by 2 mg each day to the lowest effective maintenance dose. For pain from nerve compression, start at 8mg. For spinal cord compression, start at 16 mg.
- Prednisolone-Use when dexamethasone is not available.

A conversion rate of 4 mg Dexamethasone to 30mg Prednisolone can be used.
Give steroids during day time, caution related to GI side-effects and long-term use side-effects should be taken.

Muscle Relaxants

- Diazepam-Adults: 5mg orally 2 or 3 times a day
- Lorazepam-0.5-2 mg oral or intravenous every 3 to 6 hours

Side effects: can cause drowsiness and ataxia

2.4.4. Pain Emergencies, Breakthrough Pain and Procedural Pain

Pain Emergency

The goal is to control pain (i.e. to get pain score below 5 out of 10)

- If patient is in excruciating pain (pain score = 9 or 10), it is considered a pain
- emergency
    - Administer morphine rescue dose intravenously (IV)
    - Remember to convert oral dose to IV dose by dividing by 2-3
- Otherwise rescue doses can be oral
- Wait for dose to take effect (10 minutes for IV and 30 minutes for oral) and then reassess

Breakthrough pain: a sudden, temporary flare of severe pain that occurs on a background of otherwise controlled pain. May be more common during the first three days of treatment as morphine dose is titrated from starting dose to effective dose.

- 50-70% of patients with chronic cancer-related pain also experience episodes of breakthrough pain
- Associated with greater pain-related functional impairment, worse mood, and more anxiety
- Healthcare providers routinely under-diagnose and under-treat breakthrough pain

Rescue Dose

- Rescue dose: a dose of immediate-release morphine that is the same as the dose given every 4 hours and can be given as often as required to treat breakthrough pain
- The rescue dose must be increased whenever the regular dose is increased
- Rescue dosing is suitable for all immediate-release opioids, not just morphine
- A frequency of 4 or fewer rescue doses per day is normal
- If a patient requires more than 4 rescue doses per day, you should increase the background dose
- Add total rescue doses to normal daily dose and divide by 6 or 30-50% increment in dose
- Example: in a patient taking 10mg every 4 hours and 5 rescue doses of 10mg,
- new daily dose is (10*6) +(10*5) =110mg, given as 15 or 20mg every 4 hours
- If there is no need for rescue doses, you may try a small reduction in background dose

Procedural pain

- Procedural pain: Pain precipitated by a particular activity or procedure, such as dressing change, washing, change in position, eating, or dis impaction
- Can be anticipated
- Supplement regular analgesic regimen with a rescue dose given 20-30 minutes before the activity

End-of-dose failure: Effect of analgesia wears off after a few hours and pain returns

Treatment

- Change to a longer-acting medicine
- Increase the dose of the current medicine
- Reduce the dosing interval

2.4.5. Non - Pharmacological Pain Management

- Pain is influenced by psychological, cultural, social and spiritual factors.
- Complementary or alternative therapies are increasingly being used to alleviate pain. These are therapies used together with conventional medicine but do not replace this.
- There are a whole range of techniques and expertise that exists to complement the pharmacological and interventional approaches for pain management. Not

Non-pharmacologic approaches can be categorized into:

- Biochemical therapies like herbs, dietary supplements, flower essences, and aromatherapy oils.
- Biomechanical therapies like massage, traction, manipulation and mobilizing, deep breathing.
- Bioenergetics therapies like acupuncture, Transcutaneous electrical nerve stimulation (TENS), Ultrasound, therapeutic touch, heat cryotherapy
- Lifestyle therapies like environment, diet, exercise and dance.
- Mind-body techniques such as spiritual, social support, meditation, relaxation and imagery, music, patient education.
- Some complementary therapies, such as herbs, are used commonly across Africa. Prolonged bed rest and bracing result in immobilization, which are deleterious to muscle and soft tissue wellbeing and have no scientific role in healing or pain relief.

Chapter 3.
Symptom management
3.1 Management of Gastro-Intestinal symptoms

Nausea and Vomiting

Causes

- Infections
- Raised intracranial pressure
- Anxiety
- Chemotherapy, radiotherapy, Immunotherapy
- Gastric irritation
- Constipation

Treat: treat a treatable underlying cause with standard guideline

Care

- Ensure that the patient is taking medicines as prescribed.
- Avoid smells that cause nausea, for, e.g., the smell of cooking, the smell of
- phenol, Dettol etc.
- Give small portions of food at frequent intervals at least 8 meals per day.
- Give liquid in small quantities at intervals of half an hour.
- Give the patient the food that he prefers
- Make sure that the patient takes plenty of fluids
- Try to make the patient sit up while eating and let him not lie down immediately after food
- Try ginger, such as candied ginger or ginger tea. Real ginger not ginger flavoring helps to reduce nausea.
- When the patient is feeling better, begin eating clear soups, mild foods, and liquids until all symptoms are gone for 12 to 48 hours (about 2 days).
- Avoid milk, alcohol, caffeine, carbonated beverages, and most fruit juices.
- Good oral hygiene (especially after vomits);
- Relaxation / distraction techniques;
- Acupuncture and hypnosis may have a role for practitioners who have these skills;

Prescribe: prescribe anti-emetics based on the standard treatment guideline

Oral Candidiasis/ Thrush

Causes

- Prolonged use if corticosteroids
- Diabetes mellitus
- Dry mouth
- Immune suppression

Patients may or may not have oral symptoms like pain and difficulty in swallowing (esophageal Candidiasis).

Features

- White adherent patches
- Coated on the tongue and oral mucosa
- May appear red and ulcerated

Care:

Giving good mouth care is essential to the wellbeing of debilitated patients. Proper use of steroids

Prescribe

- Topical: Nystatin Suspension 1-2 ml Q4H
- Systemic - Fluconazole 150mg stat or 50mg daily for 7-14 days depending on the severity of the infection.

Dry Mouth (xerostomia)

Causes

- Infections: viral, bacterial and fungal
- Drugs: Anticholinergics, Anti-depressants, opioids
- Dehydration
- Mouth breathing
- Poor nutritional status
- Cancer therapy (head and neck radiotherapy and chemotherapies)

Treat

Treat a treatable underlying cause with national guidelines.

Care

- Maintain frequent attention to good oral hygiene
- Review and alter unnecessary current medications
- Stimulate salivary flow
- Rehydrate with ice chips
- Modify diet. Consider chewing gums, pineapple, mild citrus drinks, soda water and normal saline

Halitosis

Causes:

- Dietary - a frequent cause is the use of garlic or spices
- Dental/periodontal problems
- Infected teeth, gums, oral mucosal, or oral carcinoma. Thrush alone is unlikely to
- cause halitosis
- Upper GI causes
- Bowel obstruction causing fecal vomiting
- Anaerobic infection of the lungs such as bronchiectasis

Treat: treat a treatable cause with national guidelines.

Care

- Assist the patient in brushing and cleaning the mouth, tongue and teeth.
- If brushing is difficult, then a small gauze or clean cloth can be used.
- For a coated tongue, a soft baby's toothbrush or clean cotton cloth can be used.
- Rinse the mouth before and after food using warm water or saline solution.
- If the mouth is dry, saliva production may be stimulated by sucking a piece of pineapple or sipping fresh lime juice. Be careful with this if there are ulcers or pain
- Frequent sipping of water can also be helpful, so ensure the cup is nearby.

Anorexia

Causes

- Extensive malignancy (can be a presenting symptom)
- Uncontrolled symptoms
- Psychological, emotional and spiritual distress e.g., anxiety and depression
- Drugs, e.g., chemotherapy, immunotherapy, digoxin

Clinical features

- A reduced interest in food which at its most severe may manifest as nausea
- Often associated with taste changes
- May increase (appetite diminishes) as the day goes on
- Distinguish from mouth problems, difficulties with swallowing, and early satiety due to gastric stasis

Treat: treat a treatable underlying cause

Care:

- Small but frequent meals
- Energy-dense food
- Limit fat intake
- Avoid extremes in the smell
- Pleasant environment

Prescribe

- Dexamethasone may be used at doses of 2-4 mg or Prednisolone 10 - 30 mgod PO daily as an appetite stimulant and to treat nausea. Its effect is generally short. Side effects limit its use as an appetite stimulant.

Constipation

Causes

- Inactivity, immobility, weakness
- Dehydration due to poor fluid intake, vomiting, polyuria, fever
- Hypercalcemia
- Spinal cord compression or sacral nerve root lesion
- Concurrent disease including painful anal conditions, neurological disorders
- Lack of privacy
- Changes in the type of food.
- Decreased intake of food and water
- Lack of adequate fiber in food
- Drug induced (Opioids, antidiarrheal, anti-depressants)

Treat: treat treatable underlying cause with national guideline

Care

- Ensure privacy for the patient and provide a commode or bedpan, if required.
- Exercise the body according to the patient's ability. Even bedridden patients should be given some light exercises.
- Evaluate reliance on enemas for elimination
- Evaluate usual dietary habits, eating habits, eating schedule and liquid intake.
- Evaluate current medication usage that may contribute to constipation.
- Maintenance of an adequate bowel protocol usually requires a prophylactic stool softener and stimulant
- Encourage patients to drink plenty of fluids as tolerated while increasing their activity as appropriate
- High fiber food (e.g., raw fruits, fresh vegetables, whole grains) to be taken with adequate fluids
- Consider enema and suppositories if the patient is no longer able to tolerate oral medications, or they have become ineffective.
- Digitally removal of a fecal impaction as ordered patient is no longer able to tolerate oral medications, or they have become ineffective

Prescribe

- Bisacodyl 5mg at night, increasing to 15 mg if needed.
- Senna one to two tablets at night, increasing if necessary.
- Glycerol or bisacodyl suppositories can be helpful if available.

Diarrhea

Causes

- Infections
- Side effects of some drugs, e.g., chemotherapy, immunotherapy, antibiotics, PPIs, NSAIDs
- Excess laxative use
- On initiation of enteral feeding
- Effects of some tumors, e.g., carcinoid, mucus secretion in rectal cancer

Treat: treat the treatable underlying cause

Care

- Provide privacy for the patient
- Rice, bread or potatoes are good for diarrhea.
- Bananas and tomatoes are good for replacing potassium.
- Yogurt is better tolerated than milk and cheese.
- Ensure proximity for the toilets/ bedpan / commode
- Ensure the patient has supportive clothing or pads.
- Assess perineal skin integrity
- Treat any perineal irritation with moisture barrier ointment.
- Educate patient and family about cleaning the perineum carefully and gently after defecation
- Advice to eat small frequent bland meals. Low residue diet – potassium-rich
- Avoid intake of hyperosmotic supplements (concentrated juices, concentrated beverages)
- Increase fluids in diet at least 3 liters/day which includes electrolyte drinks
- Discourage the use of pads, diapers, or collection devices as soon as possible.
- Gradually reintroduce proteins and then fats to the diet as diarrhea resolves, while cooking and storing food

Prescribe

- Loperamide 2mg t.d.s. and after each loose stool, up to 16 mg/day

The following two should be prescribed for palliative patients with diarrheal.

- Codeine 10mg t.d.s. (up to 30mg four hourly)
- Oral morphine2.5-5 mg every four hours (if severe).

Fatigue

Causes

- Multiple causes, often obscured by coexisting disease processes
- Anemia
- Pain
- Emotional distress
- Sleep disturbances
- Poor nutrition.

Treat: treat the underlying causes.

Care

- Interventions include energy conservation and physical exercise, and stress reduction by relaxation and meditation.

Prescribe

- Can give low doses of psychostimulants, e.g., methylphenidate (Ritalin) or anti-depressants.

3.2 Management of respiratory symptoms

Cough

Causes

- Respiratory infections
- Bronchospasm
- Bronchial obstruction (Asthma, COPD, Malignancy)
- Cardiac causes
- Drug related like ACE inhibitors
- Oesophageal reflux

Treat: treat the treatable based on the standard guideline

Care:

- Avoid smoke near the patient
- Help the patient to cough up sputum by sitting up position
- Instruct the patient to cough in the direction away from caregiver
- Clapping on the patient's back with cupped hands in each position and using steam inhalation if the sputum is thick. (Chest physiotherapy)
- 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). Add sugar or honey to taste.
- 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.
- Honey, ginger, and cinnamon: Add one teaspoon of ginger powder or cinnamon powder to 150 mL honey and stir. Take 5–10 mL of the mixture 4-hourly for 5 days.

Prescribe:

- For dry cough - give Dextromethorphan syrup, Codeine and Morphine
- For productive cough- Investigate the patient to rule out infections

Shortness of breath

A subjective sensation that patients describe as chest tightness, shortness of breath, air hunger, inability to take a deep breath, a feeling of suffocation or smothering, or an inability to get enough air. Shortness of breath most of the time can cause anxiety for the patient and their family.

Causes:

- Pulmonary infections
- COPD
- Heart Failure
- Pleural Effusion

Treat: treat the treatable based on the standard guideline

Care:

- Help the sick person in semi-sitting or sitting position
- Use extra pillows or some back support
- Open windows to allow in fresh air and fan
- Chest physiotherapy
- Give patient water frequently (it loosens sputum)

Prescribe:

- Administer oxygen as necessary
- Morphine 2.5-5 mg PO every four hours
- Diazepam 2.5mg TDS
- Lorazepam 0.5 – 2 mg po BID (for anxiety)

Pulmonary Secretion

Causes

- Gastric reflux
- Pulmonary edema
- COPD
- Broncho alveolar carcinoma
- Bronchial mucosal inflammation/infection

Treat: treat the treatable based on the standard guideline

Care:

- Postural drainage: Chest physiotherapy (includes postural drainage, chest percussion and vibration, coughing and deep breathing exercises) appropriate to the patient's condition is valuable in managing respiratory secretions.
- Hydration: orally or intravenously is a useful treatment to this problem. Dehydration can increase sputum viscosity and exacerbate difficulties with expectoration.

Prescribe:

- Use an antisecretory drug to reduce production of respiratory secretions: Hyoscine butyl bromide. Adults: start at 10 mg three times a day; can be increased to 40 mg three times a day
- Humidified oxygen. Inhaled oxygen is a helpful comfort measure to reduce symptoms of upper airway drying when oxygen is being administered (the patient will need mouth care if using oxygen for long periods of time).

Haemoptysis

Causes:

- Acute Bronchitis,
- Pneumonia,
- Lung cancer
- Pulmonary embolism.

Treat: treat the treatable based on the standard guideline

Care:

- Address the fear and anxiety.
- Use colored towels (preferable green towel) or bedding to cover the bleeding in order to minimize the anxiety and fear associated with seeing the bleeding.
- Keep the patient alert and conscious to avoid further aspiration

Prescribe

Mild to Moderate:

- Cough suppressant
- Tranexamic Acid or Ethamsylate
- Steroids (Dexamethasone at a dose of 2-4 mg) could show some benefit for further treatment, consult for an expert opinion.

Severe/Massive Hemoptysis:

- Massive hemoptysis is defined as the expectoration of over 200 ml of blood in 24 hours. A trial of benzodiazepine (Lorazepam 0.5 mg to 2 mg PO or diazepam 10 mg PO)
- Midazolam
- Refer the patient

3.3 Management of Cardiovascular Symptoms
Palliative Care role in heart failure

All patients and family members should be taught about disease progression and the risk of sudden cardiac death. For some patients, improving quality of life is as important as increasing the quantity of life. Thus, it is important to determine patients' wishes about resuscitation (eg, endotracheal intubation, CPR (cardiopulmonary respiration) if their condition deteriorates, especially when HF is already severe.

All patients should be reassured that symptoms will be relieved, and they should be encouraged to seek medical attention early if their symptoms change significantly.

General Measures

- They should be educated on the importance of drug adherence; warning signs of an exacerbation and the patient and family should be involved in treatment choices.
- Sodium restriction
- Appropriate weight and fitness levels
- Correction of underlying conditions

Chest Pain

Causes

- Cardiac issues
- Lung/pleural diseases
- Gastro-esophageal origin
- Musculoskeletal apparatus
- Spinal and intercostal nervous system
- Functional chest pain

Treat: a treatable underlying cause

Care

Certain findings raise suspicion of a more serious etiology of chest pain:

- Abnormal vital signs (tachycardia, bradycardia, tachypnea, hypotension)
- Signs of hypoperfusion (eg, confusion, ashen color, diaphoresis)
- Shortness of breath
- Hypoxemia on pulse oximetry

- Asymmetric breath sounds or pulses
- New heart murmurs
- Pulsus paradoxus > 10 mm Hg

If you found the above signs of heart attack please it is an emergency

case

Prescribe

Please refer the patient for emergency care

Edema

Red flags

Certain findings raise suspicion of a more serious etiology of edema:

- Sudden onset
- Significant pain
- Shortness of breath
- Fever
- History of a heart disorder or an abnormal cardiac examination
- Hemoptysis, dyspnea, or pleural friction rub
- Hepatomegaly, jaundice, ascites, splenomegaly, or hematemesis
- Unilateral leg swelling with tenderness

If you found the above findings please urgently refer for Emergency care

Causes

Generalized edema is most commonly caused by

- Heart failure
- Liver failure
- Kidney disorders (especially nephrotic syndrome)

Localized edema is most commonly caused by

- DVT or another venous disorder or venous obstruction (eg, by tumor)
- Infection
- Angioedema
- Lymphatic obstruction
- Chronic venous insufficiency may involve one or both legs.

Treat: a treatable underlying cause

Care

- Patients with heart failure should eliminate salt in cooking and at the table and avoid prepared foods with added salt.
- Fluid restriction
- Elevate your arms or legs on pillows or blankets to keep them elevated comfortably.
- Wear pressure stockings
- Stay active. Do not stand or sit for long periods of time
- Keep your skin moist using lotion, cream, or ointment
- Protect the patient's hygiene
- Every 2 hrs change the patient position

Prescribe

Refer for advanced care

Paroxysmal Nocturnal Dyspnea

It is characterized by being awakened during sleep with severe shortness of breath, gasping for air, coughing, and feeling the need to sit up, stand up, and/or open a window for air—all of which may help improve breathing after a few minutes.

Causes

- Sleep apnea
- Asthma
- Pulmonary embolism (a blood clot in the pulmonary artery that leads to the lungs)
- Diastolic heart failure, caused by stiffening of one of the ventricles (chambers) of the heart
- Acute cardiac ischemia (insufficient blood flow to the heart)

Treat: a treatable underlying cause

Care

- sleep easier by raising your head by using more pillows to keep your chest elevated
- Avoid smoking, and alcohol.
- Maintain a healthy weight.
- Eat a low-fat diet with plenty of fruits, vegetables, whole grains, and lean proteins.
- Avoid diet salt.
- Limit fluids.
- Stay physically active.
- Take steps to manage stress.

Prescribe

Please refer for advanced care

3.4 Management of Urologic symptoms
Hematuria

Causes:

- Tumor (renal, ureteric, bladder, prostate)
- UTI
- Calculi
- Trauma
- Drug-induced (Warfarin and NSAIDS)
- Glomerulonephritis

Treat: treat the treatable based on the standard guideline.

Care:

- If self-limiting, reassure patients and family.
- We can prevent cyclophosphamide associated hematuria by sticking to rehydration protocols
- If bleeding is due to drugs, discontinue the causative drug
- Evacuate clots using large bore (22Fr) Foley catheter (for suprapubic catheterize patient
- Irrigate with saline 0.9% continuously until urine clears

Prescribe:

1.Tranexamic acid 1g TID PO:

- avoid if bleeding is renal in origin because of risk of ureteral obstruction
- stop if no effect after 1 week
- continue for 1 week after bleeding has stopped, then discontinue
- continue long term (500mg TID) only if bleeding recurs and responds to second course of treatment

2.Consider transfusion for symptomatic anemia and thrombocytopenia

Bladder spasms

Causes

- Urinary tract infection
- Tumor infiltration of bladder or rectum
- Urinary catheter
- Radiation cystitis
- Neurological cases

Treat: treat the treatable based on the standard guideline.

Care:

- Change the catheter for a smaller one.
- Partially deflate the balloon (the inflated balloon can cause spasm by irritation of the bladder neck).
- Use bladder washouts for debris in the bladder.
- Strap catheter to leg to avoid traction on the bladder trigone area.

Prescribe:

- Lidocaine (lignocaine) bladder instillation 20mL 2% lidocaine (diluted if required in saline) - clamp, if possible, for 20 min-1h, repeated as necessary.
- Antimuscarinic drugs e.g. hyoscine butylbromide 40-120mg/24h

Dysuria

Causes

- Infection (UTI)
- tumor infiltration of bladder
- Radiotherapy cystitis
- Chemotherapy (cyclophosphamide)

Treat: the treatable based on the standard guideline.

Care:

- Drink plenty of water
- Use bathroom when needed
- Be relaxed during urinate
- Wipe front to back for females
- Wear cotton based and loose-fitting underwear
- Avoid alcohol, smoking and caffeine

Prescribe:

- NSAIDs or corticosteroids may help if inflammation present e.g., tumor infiltrating bladder or urethra, radiation cystitis.
- Lidocaine gel in an appropriate syringe may be used PRN. (explain)

Urinary Incontinence

There are several types of urinary incontinence, including:

- stress incontinence – when urine leaks out at times when your bladder is under pressure; for example, when you cough or laugh
- urge incontinence – when urine leaks as you feel a sudden, intense urge to pee, or soon afterwards
- overflow incontinence (chronic urinary retention) – when you're unable to fully empty your bladder, which causes frequent leaking
- total incontinence – when your bladder cannot store any urine at all, which causes you to pass urine constantly or have frequent leaking

It's also possible to have a mixture of both stress and urge urinary incontinence.

Causes:

- non-specific conditions
- Age
- neurological or pelvic problems.
- constipation
- UTI
- spinal cord compression - other neurological signs often present
- vesico-vaginal fistula
- over-use of hypnotics or sedation causing nocturnal incontinence
- causes of polyuria e.g. hypercalcemia, diabetes

Treat: the treatable based on standard guidelines.

Care:

- Bladder training, to delay urination after you get the urge to go. You may start by trying to hold off for 10 minutes every time you feel an urge to urinate. The goal is to lengthen the time between trips to the toilet until you're urinating only every 2.5 to 3.5 hours.
- Scheduled toilet trips, to urinate every two to four hours rather than waiting for the need to go.
- Fluid and diet management, to regain control of your bladder. You may need to cut back on or avoid alcohol, caffeine or acidic foods. Reducing liquid consumption, losing weight or increasing physical activity also can ease the problem.
- Pelvic floor muscle exercises (Kegel exercises)- Tighten (contract) the muscles you would use to stop urinating and hold for five seconds, and then relax for five seconds. (If this is too difficult, start by holding for two seconds and relaxing for three seconds.). And then Work up to holding the contractions for 10 seconds at a time and aim for at least three sets of 10 repetitions each day.

Prescribe:

- NSAIDs can help with an unstable bladder.
- Antimuscarinic drugs at night for nocturnal incontinence:

amitriptyline 25mg at night

3.5 Management of neurological symptoms

Seizure

Causes

- Previous epilepsy, brain trauma or surgery, brain tumor (primary or secondary)
- Drugs which lower seizure threshold: e.g., phenothiazine, tricyclics, tramadol
- Drug interactions:
- Anticonvulsants have many variable and unpredictable interactions
- significantly carbamazepine and phenytoin can reduce the effect of steroids
- Drug withdrawal, e.g., steroids, alcohol
- Metabolic disturbance, e.g., hypoxia, hyponatremia, hypoglycemia

Treat: a treatable cause with standard guideline

Care

- First aid precautions
- Explanation and reassurance
- Protect airway
- Oxygen if cyanosed
- Check blood sugar
- Clear explanation and support for patient and family regarding management

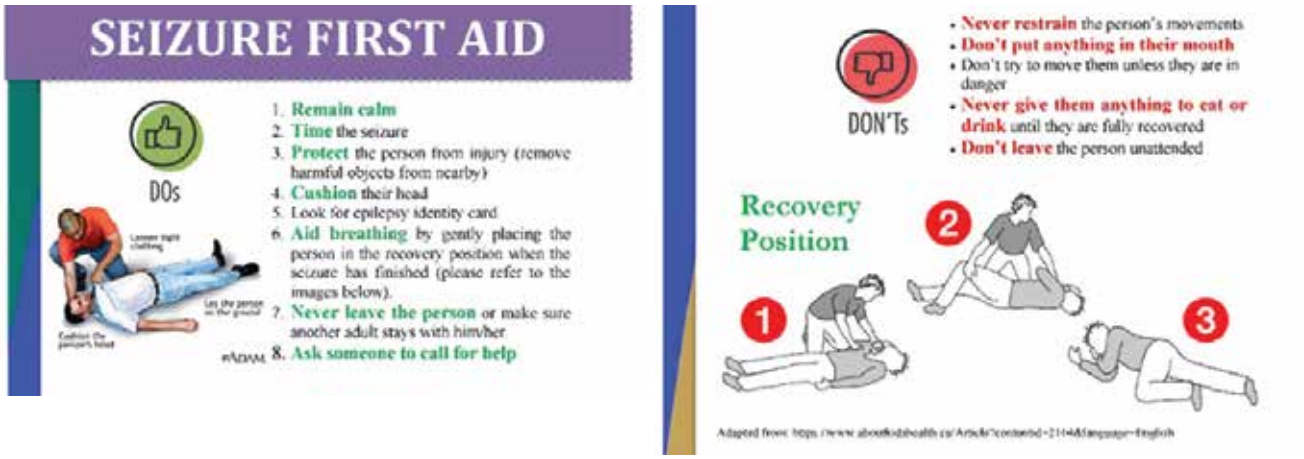


Figure illustrate the seizure first aid Do and Don't practice

Prescription for acute

- Sodium Valproate 150-200 mg bid PO (maximum daily not more than 1400mg)
- Diazepam for acute cause 5 to 10 mg IV once, then refer for advanced care

Hiccup

Causes

- Diaphragmatic or phrenic nerve irritation
- Raised intracranial pressure
- Brain stem CVA or tumor
- Metabolic (uremia, hypokalemia, hypocalcemia, hyperglycemia, hypocapnia)

Treat: a treatable underlying cause with standard guidelines.

Care

- 'Grandmother's remedies' e.g., sipping cold water, crushed ice, spoonful of granulated sugar. These mostly cause pharyngeal stimulation and are often effective, at least temporarily
- Breath holding

- Valsalva maneuver
- Breathing into bag
- Biting lemon
- Ice water gargles
- Fright
- Pulling knees to chest

Prescribe

- Metoclopramide 10-20mg tids/qids PO
- Haloperidol 1.5-3 mg nocte PO
- Gabapentin 400mg tids PO for 3 days
- Levomepromazine 6.25 – 12.5mg daily PO
- Baclofen 5-20mg tids PO
- Nifedipine 10-20mg tids PO

Stroke

Causes

- Brain infarction (84%),
- Intracerebral bleeding (7%),
- Subarachnoid hemorrhage (7%), vasculitis, dissection and sinus thrombosis.

Treat: a treatable underlying cause

Care: They need care on the following conditions

- If the patient is hypertensive, control the blood pressure
- Loss of Consciousness (comatose patient care)
- Aphasia and Dysarthria (speech therapy)
- Physiotherapy support
- Incontinence and Constipation care
- Nutrition support
- Refer to advanced care facilities

Prescribe

Follow the national guideline

Dementia

A syndrome brought on by a brain disorder, typically one that is chronic or progressive, and in which multiple higher cortical functions, such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment, are disrupted. Not impaired is consciousness.

Clinical Features:

Mild

Memory Loss, Personality changes and Spatial Disorientation

Moderate

Aphasia, Apraxia, Confusion, Agitation, Insomnia

Severe

Restiveness, Incontinence, Eating Difficulty, Motor Impairment Terminal Bedbound, Mute, Dysphagia, recurrent Infection.

Principles of Management:

1. Reinforce continuity of care
2. Emotional Support to patient and family
3. Refer if specialists needed

4. Early and moderate dementia: Keep up the activity level, provide support, and manage depression and anxiety
5. Advanced dementia: have also the risk of mortality

3.6 Management of skin problems

Wound Care

Unsightly and painful wounds could adversely affect self-esteem and body image causing patients to isolate themselves. A fumigating wound with mal-odor, exudates, infection, and maggots and bleeding add to the misery of advanced and uncontrolled metastasis disease.

Causes

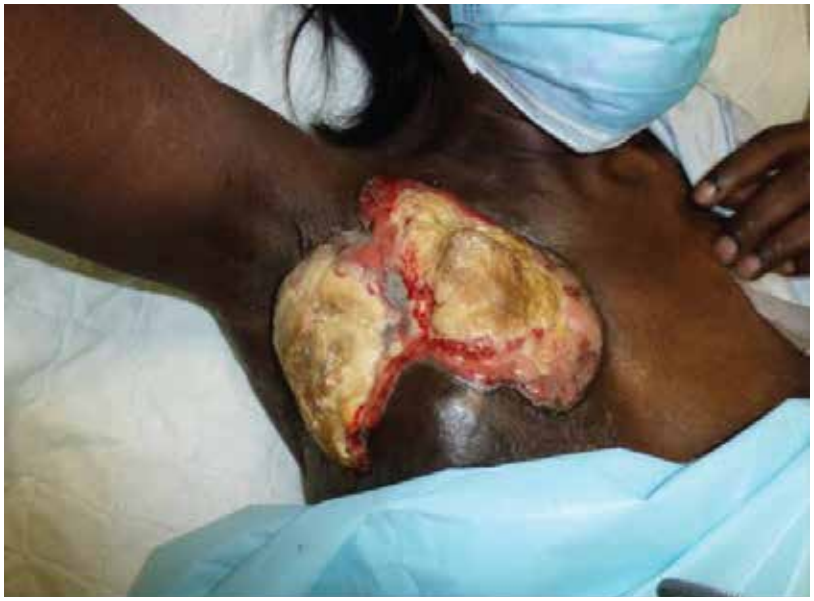
Infection
Proliferative (primary or secondary) malignant

Assessment

- Physical problems – pain, mal-odor, bleeding, infection, exudates and maggots
  - Wound location: whether on exposed part of the body
  - Wound appearance - size, necrotic tissue, fistula
  - Condition of surrounding skin
  - Potential for complications such as hemorrhage
- Psychological problems - shame, guilt, altered body image, fear of death, depression, anxiety and isolation.
- Social problems - isolation, stigma, effect on family, fear of contagion
- Spiritual issues - interference with religious rights, belief that it is punishment from God, losing or developing faith in God, existential dilemmas

Treat

- Treat a treatable underlying cause with nation guideline
- Superficial pain burning/stinging - local application of 0.25% Bupivacaine, Lignocaine jelly or opioid and soak 10 minutes before dressing. Ketamine can be given sublingually (0.25 mg - 0.5 mg/ kg/dose).



Picture: illustrate skin wound

Care:

If their Maggots

Prevention of maggot infection is better than cure. The following steps should be used for infection, if present.

- Wounds should be covered with dressing all the time and changed daily.
- Apply or flush plain turpentine oil into the wound with a syringe if there are maggots present. If turpentine spills accidentally into the oral cavity, warn them not to swallow, cover the patient's eyes, nose, and ears with pads and because it will irritate their mouths. Following the application of turpentine, wait 10 minutes. Maggots should be removed with forceps.
- When there is a lack of oxygen supply and irritation from turpentine vapor, maggots emerge from the tissue's concealed pockets. To get rid of all the maggots, the turpentine flushing process must be repeated for three to four days. When entirely removed, instruct the career on how to properly clean and bandage a wound.

If there Malodour

Usually caused as a result of anaerobic bacterial growth in dead tissues. This can be controlled as follows:

1. Daily bathing followed by dressing
2. Using regular saline for cleaning. At home by using 2 teaspoons of salt for 1000ml of boiled and cooled water.
3. Use gauze to carefully clean the wound. On the wound, apply metronidazole gel powder. Prepare the sterilized gauze at home with old cotton cloth that has been well cleaned with soap and water and dried outside. Cut the clean cotton fabric into small pieces, steam it for 30 minutes, and then store it in a spotless airtight container.
4. Apply lignocaine jelly diluted with metronidazole gel to a wound that is dry and inflamed (benefit will be noticed only after 12 hours).
5. Till the malodor goes away, dress at least twice daily.
6. Metronidazole gel is pricey and contains less metronidazole per gram than tablets do. Tablets or capsules are preferred than gel for local application.
7. For exudates, routine dressing changes and the use of absorbent pads

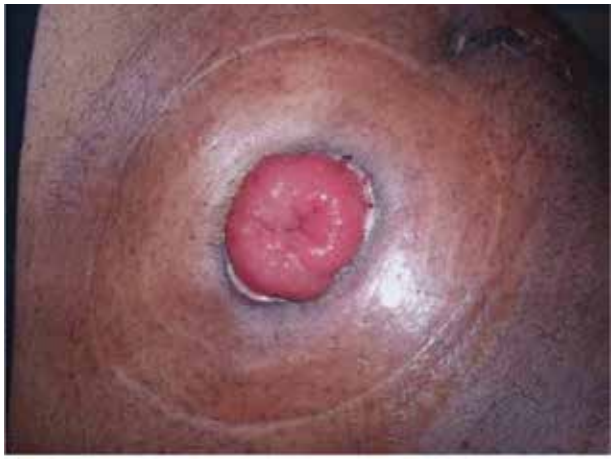
If there Bleeding

1. Soak the dressing in regular saline and remove it slowly to avoid bleeding.
2. If bleeding is present, push on the wound for 10 minutes. Keep applying pressure if the bleeding persists.
3. Use a dressing with sucralfate powder since it coats the wound locally.
4. You can dilute injection feracrylum 1% (hemlok) with water and use it as a soak. For localized use, combine 1 ml of hemlok with 100 ml of sterile water.
5. As adrenaline can absorb through a raw cut and create an increase in pressure and bleeding, adrenalin packs should be used with caution. The effects of adrenaline also last only briefly.

Stoma Care

Types of stomas

- Input and output,
- Temporary and Permanent



Picture: illustrate of post-operative stoma

Care

Post-operative stoma care

- Proper surrounding skin care
- Provide liquid diet initially followed by soft diet to alleviate the patients' psychological trauma.
- Reduce intake of certain food that cause gas and mal odor such as onion, cabbage, spicy foods, meat, egg
- Teamwork for good management between patient, family, surgeon, and nurse therapist.
- Bag care - correct size, proper cleaning with soap and water, optimum drying and emptying when 3/4th full.
  Bleeding is usually seen at the time of cleaning or changing the bag. Apply local pressure for 10 minutes and use sucralfate powder to control bleeding.
- A prolapse of 1.5 cm of stoma outside the skin level is acceptable in case of colostomy. 3.5 cm of stoma outside the skin level is acceptable in ileostomy. A prolapse of greater than 5 cm needs referral for surgical intervention

Bed Sores

Prevention and care of bedsores are the most important challenging aspects of nursing care. Damage can occur due to pressure, friction, shearing and chemicals.

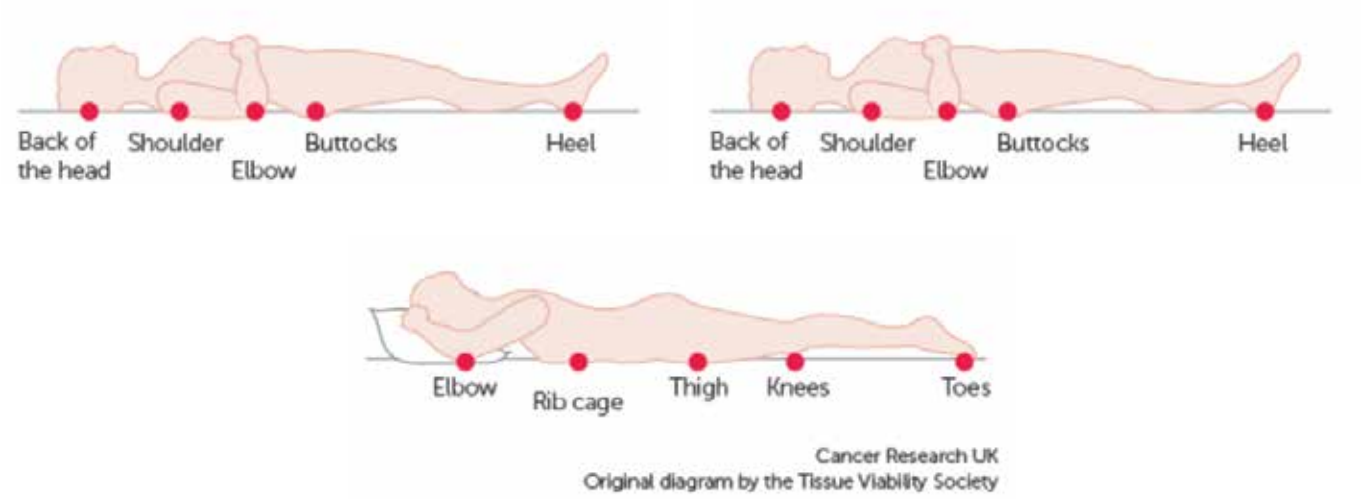


Figure: Indicates a high risk of bed sores in certain sleeping positions.

- Reduced frequent positioning
- Weight loss
- Incontinence
- Sensory loss
- Poor nutritional status
- Steroid therapy
- Cytotoxic therapy

How to prevent bed sore

1. Regular interval positional change
2. Good pain relief
3. Good skin hygiene
4. Nutritional support
5. Assess and treat incontinence
6. Assess the need for pressure relief
7. Regular observation of pressure points
8. Review medication

Care

1. To prevent further damage
2. To promote potential healing
3. To relieve pain and discomfort
4. To prevent infection
5. To control smell and discharge
6. To minimize bleeding

- Necrotic; surgical excision
- Slough; Deslough, irrigation with normal saline; foam dressing
- Infected; topical antibiotics and odor absorbing dressing
- Granulated; foaming dressing

3.7 Psychological symptoms
Management of Psychological symptoms

Depression:

Assessment

The DSM-5 outlines the following criterion to make a diagnosis of depression. The individual must be experiencing five or more symptoms during the same 2-week period and at least one of the symptoms should be either (1) depressed mood or (2) loss of interest or pleasure.

- Depressed mood most of the day, nearly every day.
- Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day.
- Significant weight loss when not dieting or weight gain, or decrease or increase in appetite nearly every day.
- A slowing down of thought and a reduction of physical movement (observable by others, not merely subjective feelings of restlessness or being slowed down).
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness or excessive or inappropriate guilt nearly every day.
- Diminished ability to think or concentrate, or indecisiveness, nearly every day.
- Recurrent thoughts of death, recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

Treat: the treatable based on standard guidelines

Care

- On-going support and counseling may be needed.
- Antidepressants take several weeks to be effective so should be tried for at least 2–4 weeks.

Prescribe

- Amitriptyline – start with 25mg at night and increase gradually to 75–150mg. (The antidepressant effect is unlikely to be seen at less than 75 mg and less than a week.)
- Imipramine, if available, is an alternative that might be less sedative.

Anxiety

Various factors contribute to causing anxiety. These include the disease, distressing symptoms, patient conditions, spiritual problems, social problems, treatments and others. Anxiety is expressed by the following symptoms:

- Anxiety out of proportion to the stress
- Persistence of symptoms for more than two weeks
- Severe physical symptoms or recurrent panic attacks
- Disruption to normal functioning

Assessment

- General symptoms included feelings of panic, irritability, tremor, sweating, lack of sleep and a lack of concentration.

The DSM-5 outlines the following criterion to make a diagnosis of Generalized Anxiety:

A. Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least 6 months, about a number of events or activities (such as work or school performance).
B. The individual finds it difficult to control the worry.
C. The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms having been present for more days than not for the past 6 months):

Note: Only one item required in children.

1. Restlessness, feeling keyed up or on edge.
2. Being easily fatigued.
3. Difficulty concentrating or mind going blank.
4. Irritability.
5. Muscle tension.
6. Sleep disturbance (difficulty falling or staying asleep, or restless, unsatisfying sleep).

Treat: the treatable based on standard guidelines

Care

- Identify their social and spiritual needs and give care respectively.
- Identify fears or worries, if present and give care.
- Massage and relaxation.
- Treat anxiety and depression, if present.

Prescribe

- Diazepam 2 to 5 mg PRN, p.o./day
- Lorazepam 1 to 2 mg PRN, p.o.bid/day
- Amitriptyline 25 to 50 mg po/day

Note: *If there is no improvement, please refer to the psychiatric department or consult senior medical staff.*

Insomnia

Causes

- It may be transient or chronic:
- Transient: secondary to life crisis, bereavement, illness
- Chronic: associated with medical or psychiatric disorders, drug intake or mal-adaptive behavioral patterns.

Assess

The DSM-5 outlines the following criterion to make a diagnosis of insomnia:

- Challenges falling asleep (onset insomnia): inability to fall asleep beyond 20-30 minutes
- Inability to maintain sleep (middle insomnia): frequent waking during the night after sleep onset beyond 20-30 minutes, and difficulty returning to sleep after mid-night waking
- Early-morning wakefulness (late insomnia): waking at least 30 minutes before the desired time and before sleep reaches 6.5 hours (often accompanied by an inability to resume sleep at all)

Treat: the treatable based on standard guidelines

Care

- Avoid screening time before the bed
- Having light dinners before bed
- Go to bed after 2-3 hrs. after meal
- Counseling
- Avoid alcohol, caffeine, and other stimulants
- Exercise regularly in the earlier part of the day.

Prescribe

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

Management of Emergencies in palliative care

The most common palliative care emergency cases are hypercalcaemia, spinal cord compression (SCC), superior vena cava obstruction (SVCO), dyspnoea, seizures, haemorrhage, psychiatric emergencies, hypoglycaemia, increased intracranial pressure, and drug toxicity/side effects.

Management Principles emergency situations requires consideration of:

- Is this an emergency case?
- Then is this a palliative care patient?
- Is this event a reversible or terminal event? (consider patient and family wish)
- If so, reversing the event is reasonable?
- Prevention of complications
- Early recognition an ABC of life care
- Appropriate responses for emergency events
- Communication for advanced care referral

Chapter 4.
Palliative care in special population
4.1 Palliative care in Children

Pediatric palliative care focuses on improving the quality of life for the child or young person and supporting their family members or careers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement.

Peculiarities pediatrics Palliative Care

- More frequent need to integrate palliative care with intensive disease-modifying or life-sustaining treatments due to unclear prognosis.
- Care often requires a dual focus on growth/development and potential for death.
- Greater emotional burden for family members and clinicians.
- Patients undergo continual developmental change: physical, hormonal, cognitive, expressive and emotional.
- Patients have changing information needs, recreational and educational needs, and modes of coping with stress. Thus, child life specialists, play therapists and behavioral specialists can greatly enhance palliative care for children.
- Patients may have congenital anomalies of uncertain type or rare genetic conditions.
- Some genetic conditions may affect multiple children in a family and create a sense of guilt in parents.
- Child care needs special approach

Pain assessment in children

There may be more than one pain origin: physical, psychological, social, spiritual. Assess, quantify and treat each pain.

Children (especially under three children) may use the word pain for discomfort caused by other symptoms.

Clinical features of child with pain

- Crying
- Groaning
- Restlessness
- Withdrawal-cannot play
- Sweating
- Holding or protecting the painful area
- Refusal to eat

Three ways to assess pain:

1. Ask the child (if able to tell)
2. Ask the family (even if the child has already told)
3. Assess yourself (least accurate)

Use pain assessment scales adapted to age

- *In children over 3 years, self-report pain scales facilitate communication from verbal children about pain, such as the modified Wong Faces Pain Scale, and the Visual Analogue scale.*

Wong Baker Faces Pain Assessment Tool

Score and interpretation:

1. 0: Relaxed and comfortable
2. 1-3: Mild discomfort
3. 4-6: Mode-rate pain
4. 7-10: Severe pain

In preverbal and nonverbal children (3 years and below), use observation methods based on behavioral response e.g., FLACC

FLACC Methods

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

Each of the five categories: (**F**) Face; (**L**) Legs; (**A**) Activity; (**C**) Cry; (**C**) Consolability, is scored from 0–2 which results in a total score between 0 and 10 (*Merkel et al. 1997*)

Pediatrics Pain Management

Analgesic therapies should be combined with appropriate psychosocial, physical, and spiritual approaches because pain has multiple dimensions. In general, we need to consider the following approaches:

- Pain assessment tools shall be age appropriate
- Aspirin is contraindicated in children less than 12 years.
- Codeine and tramadol not advised for children
- Consider the child's general health conditions and nutritional status before any analgesic drugs prescription.
- Always consult pain expert and pediatrician for your prescription of adjuvants
- Pain is managed using through two stage WHO ladder

Pharmacological:

- *WHO recommends a two-step ladder for pain control in children as many lack the enzyme needed to convert codeine into morphine, and there is no safety data of tramadol in children.*
- *WHO analgesic ladder for children whenever one drug provides no relief, then a drug combination or a change of drug is required.*

WHO Pediatrics Analgesic Ladder

Step 1 for mild pain: paracetamol and non-steroidal anti-inflammatory drugs (contra-indicated in children with thrombocytopenia).

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

Step 2 for moderate to severe pain: strong opioids in association with step 1 non-opioids, with or without adjuvants

Strong opioids

Oral morphine

Starting dose in an opioid-naïve child:

- 0.1 to 0.3 mg/kg 4 hourly above 6 months of age
- 0.05-0.1 mg/kg 4 hourly in infants <6 months
- Start with 5 mg of short-acting morphine in any child weighing 17 kg or more, 4
- hourlies
- Increase by 30% to 50% till good analgesia is obtained.
- Double dose can be given at bedtime to avoid waking the child for the night dose and the next dose administered 8 hours later.
- It can then be mixed with a small amount of juice/ soft food for easy administration.
- There is no maximum (ceiling effect) acceptable dose to control severe pain.
- Morphine does not hasten death.

Always add along with opioids:

- Antiemetic (ondansetron or metoclopramide) for the first 3 days of starting. Nausea and vomiting wear off after a few days.
- Laxatives (glycerin suppository, liquid paraffin or lactulose). Please refer your guideline for prescription.

Non-pharmacological analgesic measures

- Heat helps decrease pain and muscle spasms. Apply heat to the area for 20 to 30 minutes every 2 hours for as many days as directed.
- Ice helps decrease swelling and pain. Ice may also help prevent tissue damage. Use an ice pack or put crushed ice in a plastic bag. Cover it with a towel and place it on the area for 15 to 20 minutes every hour or as directed.
- Massage therapy may help relax a child's muscles and decrease pain.
- Physical therapy helps a child with exercises to improve movement and strength and decrease pain.

- A transcutaneous electrical nerve stimulation (TENS) is a portable, pocket-sized, battery-powered device that attaches to a child's skin. It is usually placed over the area of pain. It uses mild, safe electrical signals to help control pain. Please consult a physiotherapist for details.
- Relaxation exercises teach a child to breathe in deeply until his or her stomach rises a bit and then breathe out slowly. To relax muscles, the exercises teach your child to tense his or her muscles and then relax them. Guide your child through this exercise starting from foot muscles, slowly going up the leg. Then move to the muscles of the middle body, arms, neck, and head.
- Distraction helps a child learn to focus his or her attention on something other than pain. Distraction includes activities such as painting, playing board or video games, or watching TV. Visiting with friends or playing with animals may also be a form of distraction.
- Guided imagery teaches a child to imagine a picture in his or her mind. Your child learns to focus on the picture instead of his or her pain. It may help your child learn how to change the way his or her body senses and responds to pain.
- Music therapy may help lift your child's energy levels and mood. Music may help take a child's mind off his or her pain. Help a child pick song that make him or her happy, calm, or relaxed. You may play your child's favorite songs just before a procedure or when he or she is in pain. Music may be used with any of the other techniques, such as relaxation and distraction

Common Symptoms of Critically Ill Children

The care of a seriously sick child is demanding for everyone involved and is accompanied by sadness when the child is dying or after they have died. This sadness can sometimes take a toll on the body and manifest itself as a heavy feeling in the heart or stomach, feeling tired, sick, headaches and no energy at all. Loss of appetite, diarrhea, dehydration, constipation, oral thrush and nausea and vomiting are common clinical problems of critically ill children. However, those clinical symptoms have similar clinical features, care and prescribing approaches as adults so please refer to the symptom management part.

Dehydration

This is when the body loses a lot of fluid through passing fever, diarrhea and or vomiting. There are two important signs of dehydration

Some Dehydration: Signs

- Level of consciousness-Restless and irritable
- Eye Sunken-Sunken eyes
- Ability to drink-Eager and thirsty
- Skin pinch (turgor)-Skin returns to normal slowly, about less than two (2) seconds

Severe Dehydration: Signs

- Level of consciousness-Lethargic or unconscious
- Eye Sunken-Very sunken
- Ability to drink-Poor or unable
- Skin pinch (turgor)-Very slow return to normally takes more than two (2) seconds

Management

Pharmacological

Treat: a treatable underlying cause

Non-pharmacological

- Give the child small sips of water or ORS
- Refer to the clinic or hospital for management of severe dehydration

4.2 Palliative care in geriatric

Palliative care is a skill integral to geriatric medicine, often targeted for people greater than 60 or 65 years of age. Older people reaching the end of life frequently develop multiple debilitating conditions such as fragility syndrome and diseases such as dementia, osteoporosis, and arthritis, and they often do so over longer periods of time. They may therefore have palliative care needs at any point in the illness trajectory and not just the terminal phase. As such, palliative care should be integrated into chronic disease management.

Common concerns among a Geriatric Population

Physical issues

Frailty Syndrome

The elderly person will have general weakness, loss of skeletal mass, weight loss, fatigue, slower activity and increased vulnerability to morbidity and mortality.

- Adequate nutrition, rest and mild exercise are helpful in Frailty Syndrome.

Cardiac Issues

The elderly is prone to heart attack and generally suffer from Hypertension and Dyslipidemia.

- This will need monitoring and medical managed.

Anemia: nearly 40% of geriatric population suffer from anemia. The causes are chronic diseases, poor diet and inadequate intake of food.

- Eating a balanced diet, maintaining appropriate weight, exercising regularly, and not smoking or drinking excessively while getting enough sleep and taking a daytime nap if necessary is the secret of good health at this age.
- the elderly should be advised to rest frequently as well as sit and stand up slowly to avoid dizziness.

Respiratory Issues

COPD is one of the most common causes of mortality and morbidity among the elderly. Usually, COPD patients have poor health status and quality of life due to the presence of two or more co- morbidities and poor activities of daily living. Swallowing impairment is also a common cause of aspiration induced pneumonia in the aged.

- Refer to the symptom management section in this document.

Urinary Issues

More than 2.5 million persons over 60 years of age suffer from bladder control problems and keep on hiding it for years out of shame. Many also have repeated urinary infections.

- Refer to the symptom management section in this document.

Gastro- Intestinal Issues

The elderly is more constipation prone. Dyspepsia and GERD are also issuing that require attention as they impact on quality of life. Dry mouth also troubles the old.

- This may be managed with or without drugs.
- Refer to the symptom management section in this document.

Skin Issues

In the elderly skin becomes dry and fragile and will need frequent moisturizing. Nail care can also become an issue as some may require a caregiver to trim their nails. Skin also becomes more prone to temperature variations.

- Refer to the symptom management section in this document.

Diabetes Mellitus

Diabetes is an emerging epidemic among the elderly. Early symptoms of diabetes such as polydipsia and polyphagia are usually absent in elderly patients. The atypical symptoms of diabetes in this age group include confusion, a fall, failure to thrive, neuropathy, coronary artery disease, visual symptoms, and coma.

- Screen with symptoms and monitor with glucometer and refer for medical management.

Cancer

The incidence of cancer increases with age.

- Regular checkups to detect cancer early are a must in this age group (BPH cancer for male and colorectal Ca. and breast and cervical cancer for females according to the national guideline). While under treatment they will need careful monitoring and assessment.

Stroke

Prevention will need control of hypertension.

- Management would need physiotherapy and rehabilitation. Refer to the symptom management section in this document.

Bones, Joints, Muscles & Falls

The brittleness of bones can lead to falls and the risk of fractures.

- Preventive measures should include a balanced diet and daily intake of Vitamin D & calcium.
- Regular exercise should also be encouraged. The prevalence of arthritis is quite high among the elderly. Studies show nearly 60% of the geriatric population is affected by it. Arthritis determines quality of life and ability to live independently. It leads to unstable gait and falls that are the most common causes of elderly morbidity and loss of independence. The longer older people remain mobile less will be the cost to family and society.

Less lubrication of joints causes arthritis.

- This will need conservative or surgical management.
- A fall prevention strategy is therefore of utmost importance. It must include the care of feet, staying active, care for hearing & vision, regular review of medications, making home and surroundings safe and use of walking sticks & walkers.

<u>Psychosocial issues:</u> these include loneliness, anxiety, insomnia, confusion, phobias, agitation, depression, forgetfulness, and problems communicating.

Social interaction is the key to good mental health. For this the elderly must have regular contact with family and friends. If they cannot meet in person, a call or a letter can suffice. Today the internet and the worldwide web also keep people in touch with people and their interests. The elderly should get involved in the activities of their local society. It is necessary to plan to do something new every day and have fun. Joining a walking, coffee ceremony, and gardening, etc., are activities that are pleasurable and can keep depression and dementia at bay. Volunteering for a cause and helping others also keeps people busy and involved.

Depression

Depression is often neglected in the elderly. The symptoms include loss of confidence and feeling low, anxious or panicky. People are unable to enjoy the things you usually

do and have unexplained aches and pains. There is also a tendency to avoid people, even those close to you. Sleeping badly, loss of appetite and lack of interest in appearance and surroundings as well as feeling bad all the time about things of the past are all symptoms of depression.

Refer to the Management of psychological symptoms section of this document for further guidance.

Isolation

Due to breakdown of the joint family system and migration of the younger generation to towns and cities, elderly parents in villages are being left to fend for themselves. Too old to work and with little or no source of income they are struggling even to satisfy their basic needs. This also leads to isolation among seniors as there is no one to talk to. This makes them prone to depression.

Communication

About their needs, discussing death, spiritual needs, how they would like to exit, living wills, giving closure to life.

Spiritual issues: these include the need to receive & give love, to be understood, to be valued as a human being, to be forgiven, to have hope & trust, to explore beliefs & faiths, to express feelings honestly and to find meaning & purpose in life.
Refer to the Management of spiritual distress in palliative care section of this document for further guidance.

Safety

Elders are victimized in their own homes. Studies have shown that nearly 25% of crimes against the elderly are committed by family members - sons, daughters-in-law, neighbors, servants, etc. The causes are generally land and property disputes, caste rivalries, and rural factionalism. Nearly two-thirds of elderly women are widows whereas only 22% of elderly men are widowers.

This comes with its own social and economic problems as women tend to be more dependent and consequently more subject to abuse.

Besides the physical issues mentioned above preventive care for example dental hygiene, timely cataract surgery can avoid later vision problems; walking aids and hearing aids can facilitate functioning, while ensuring proper lighting, fixing handles in the bathroom and non-slip flooring can prevent falls should be considered in geriatric care.

Chapter 5.
Spiritual issues in palliative care

Handling spiritual issues, both of the patient and the family, is an important part of palliative care. Spirituality impacts the quality of life of patients by improving one's will to live, coping skills, sense of coherence, stress management, pain management and also helps patients develop a realistic source of hope, thus increasing satisfaction with care. Spirituality and Religion are words that are often used interchangeably, yet there is a difference.

Spirituality may be defined as "intrinsic aspect of human beings that include belief in the Creator or God/Allah, search for self-worth, meaning, purpose in life and relationship to family, others, community, society". Spirituality is expressed through beliefs, values, traditions and practices". Listening to religious music/ songs, going on a pilgrimage, reading religious books, going on pilgrimage, prayers, drinking holy water, etc. all can be considered spiritual activities in Ethiopia.

Religion may be defined as a "belief in and reverence for a supernatural power accepted as the creator of the universe; a specific unified system of belief". "Religion may be considered as a structured way of expressing our beliefs. People may belong to different religions, yet they have a common spirituality".

Spiritual issues faced by persons with advanced and terminal illness. Some of the common issues are:

- Feeling cursed
- Feeling the problems as a result of punishment, sin?
- Lack of meaning and purpose in life
- Why me
- Hopelessness or demoralization
- Despair
- Guilt/Shame
- Anger at God/others
- Abandonment by God/others
- Lack of, or seeking, forgiveness/reconciliation

Assessing Spirituality:

More than 97% of Ethiopian people are religious and spiritual care and support are needed by patients virtually all the time. Thus, good palliation begins with holistic need assessment. Spirituality through a personal choice, and subjective in nature, issues related to it need to be objectively assessed and understood.

Tools to take a spiritual history

The common spiritual support assessment tool, HOPE (Anandarajah and Hight) can be used to assess spiritual care needs.

H- Source of hope

O-organized religion

P-Personal religious practice

E-effects on medical care, end of life decision

Who can provide spiritual support?

Well trained religious or spiritual leaders in palliative care

Elements of spiritual care includes:

- Religious ritual support such as taking holy water, prayers according to the patient's religious belief and needs.
- Link with the patient's respected religious leaders
- Facilitate family, neighbor, friend support
- Reading scriptures from Bible or Quran when possible

Chapter 6.
Nutrition in palliative care

Nutrition plays a vital role in palliative care, which focuses on providing comfort, support, and quality of life for individuals facing serious illnesses, particularly those with life-limiting conditions. While the primary goal of palliative care is to improve quality of life, addressing nutritional needs remains important for several reasons:

- Maintaining optimal comfort: Proper nutrition can help alleviate symptoms such as nausea, constipation, and fatigue, which are common in palliative care patients. Adequate nourishment can enhance energy levels, promote overall comfort, and contribute to a better quality of life.
- Supporting immune function: Good nutrition can bolster immune function, helping the body fight infections and other complications that may arise in individuals with advanced illnesses. This is particularly crucial when patients are vulnerable to infections due to weakened immune systems.
- Preventing malnutrition: Palliative care patients may experience reduced appetite, difficulty swallowing, or other issues that can lead to inadequate food intake and malnutrition. Malnutrition can further worsen symptoms, impair healing processes, and weaken the body's ability to tolerate treatments.
- Enhancing wound healing: In some cases, palliative care patients may have wounds or pressure ulcers that require attention. A well-balanced diet, including sufficient protein, vitamins, and minerals, can facilitate wound healing and minimize the risk of complications.
- Emotional and psychological support: Mealtimes and the enjoyment of food can have a significant psychological impact on individuals. Preparing and sharing meals can be a source of comfort, normalcy, and social interaction for both patients and their loved ones.

Some strategies and considerations in nutrition for palliative care include:

1, Individualized assessments: A comprehensive assessment of a patient's nutritional status, including their dietary intake, weight changes, physical abilities, and symptoms, helps identify specific needs and guide interventions.

2, Symptom management: Addressing symptoms such as nausea, vomiting, mouth sores, and difficulty swallowing is crucial to optimize food intake. Medications, dietary modifications, and alternative feeding methods (such as tube feeding or parenteral nutrition) may be considered when necessary.

3, Meal planning and modifications: Modifying meals to accommodate individual preferences, cultural considerations, and physical limitations can help ensure that patients receive adequate nutrition. This may involve adjusting textures (e.g., soft, pureed, or thickened liquids), portion sizes, and meal frequency. Here are some key aspects to consider when planning and modifying meals for palliative care patients:

- Individualized assessment: Conduct a comprehensive assessment of the patient's nutritional status, dietary habits, physical abilities, and any symptoms or challenges they may be experiencing. This assessment should consider factors such as food allergies, cultural preferences, and personal beliefs about food.

- Nutrient-dense meals: Focus on providing nutrient-dense meals to maximize the nutritional content of the food consumed. Include a variety of foods from different food groups, emphasizing whole grains, lean proteins, healthy fats, fruits, and vegetables. Nutrient-dense foods help meet essential nutrient requirements even with reduced food intake.
- Textural modifications: Some patients may have difficulty chewing or swallowing due to oral or throat discomfort or other medical conditions. Modify the texture of foods to ensure safe and comfortable swallowing. This may involve pureeing, blending, or mashing foods to create smoother textures or adjusting the consistency of liquids using thickeners as needed.
- Flavor enhancement: Palliative care patients may experience changes in taste perception or loss of appetite. Enhance the flavor of meals by using herbs, spices, marinades, and condiments to make the food more appealing and enjoyable.
- Consider cultural preferences: Consider the patient's cultural background and dietary preferences when planning meals. Respect cultural beliefs and incorporate familiar foods and flavors that hold significance for the patient. This can enhance the comfort and satisfaction derived from meals.
- Small modifications for nutritional enhancement: Make small modifications to boost the nutritional content of meals. For example, adding powdered milk or protein powder to beverages, incorporating extra vegetables into soups and stews, or enriching sauces and gravies with cream or butter can provide additional calories, protein, and nutrients.

  4, Food fortification:

  Multivitamin and mineral supplements: In certain cases, palliative care patients may benefit from taking multivitamin and mineral supplements to address specific nutrient deficiencies or to support overall nutritional status. However, it is important to consult with a healthcare professional, such as a doctor or dietitian, before starting any supplements to ensure they are appropriate for the individual's needs and do not interact with any medications.

  Individual preferences and cultural considerations: Food fortification should take into accounts the individual's dietary preferences, cultural background, and personal beliefs. Incorporating familiar and culturally appropriate foods into the fortified meals can enhance acceptance and enjoyment of the meals.

Meal pattern in palliative care patient

The number of meals and portion sizes for a palliative care patient can vary depending on their specific needs, preferences, and medical condition. It's important to consider that individualized meal planning is crucial in palliative care, and recommendations should be made in consultation with a healthcare professional, such as a dietitian. That being said, here are some general guidelines to keep in mind:

- Meal frequency: Palliative care patients may have varying appetites and tolerances for larger meals. Instead of focusing on traditional three main meals (breakfast, lunch, and dinner), consider offering smaller, more frequent meals throughout the day. This can help accommodate reduced appetite and ensure adequate nutrient intake.
- Portion sizes: Portion sizes should be adjusted based on the patient's individual needs and appetite. It's important to strike a balance between providing enough food for nourishment without overwhelming the patient. Portion sizes may vary depending on factors such as the patient's age, body size, activity level, and underlying medical condition.
- Nutrient-dense foods: Emphasize nutrient-dense foods to provide essential nutrients even with reduced food intake. Include a variety of foods from different

food groups, such as whole grains, lean proteins, fruits, vegetables, and healthy fats. Nutrient-dense foods can help maximize the nutritional content of each meal or snack.

- Adaptations for swallowing difficulties: If the patient has difficulty swallowing, portion sizes and textures may need to be adjusted. Pureed or blended foods and thickened liquids can be options for patients with dysphagia.
- Consider individual preferences and cultural beliefs: Consider the patient's individual preferences, cultural background, and dietary restrictions when planning meals. Respect their choices and incorporate familiar foods and flavors that are important to them. This can contribute to their comfort and satisfaction during meals.

Food recommended for palliative patient

- Protein-rich foods: Include sources of high-quality protein in the diet to support muscle strength and healing. This can include lean meats, poultry, fish, eggs, dairy products, legumes, tofu, and nuts. Soft or pureed options may be necessary for patients with swallowing difficulties.
- Whole grains: Choose whole grain options such as whole wheat bread, brown rice, quinoa, and whole grain cereals. These provide fiber, energy, and essential nutrients.
- Fruits and vegetables: Encourage a variety of fruits and vegetables that are easy to chew and swallow. Opt for soft or cooked options if needed. These provide important vitamins, minerals, antioxidants, and fiber. Pureed or blended options can be considered for patients with difficulty swallowing.
- Healthy fats: Include sources of healthy fats in the diet, such as avocados, nuts, seeds, olive oil, and fatty fish (e.g., salmon, mackerel). These fats provide essential fatty acids and can contribute to overall caloric intake.
- Dairy or dairy alternatives: Depending on the patient's preferences and tolerances, include dairy products or non-dairy alternatives such as almond milk, soy milk, or fortified plant-based yogurts. These can provide calcium, protein, and other essential nutrients.
- Soft or pureed foods: For patients with swallowing difficulties, foods with a soft or pureed texture may be necessary. This can include mashed potatoes, smooth soups, pureed vegetables, and soft fruits. Thickeners can be used to modify the consistency of liquids if needed.
- Nutrient-dense snacks: Offer nutrient-dense snacks between meals to provide additional calories and nutrients. Examples include nut butter, cheese, yogurt, smoothies, protein-rich bars, and fortified nutrition drinks.
- Hydration: Adequate hydration is essential for palliative care patients. Encourage regular intake of water, herbal teas, fruit juices, and hydrating foods such as soups, smoothies, and juicy fruits.

Regular monitoring and adjustments to the diet should be made as the patient's condition changes.

Chapter 7.
End of life care

End of life care is a care of all those with a terminal illness or terminal condition that has become advanced, progressive, incurable and does not just equate with dying. The end-of-life care phase may last for days, weeks or months. It provides physical, mental, emotional comfort, and social support, to people who are living with and dying of advanced illness.

Signs and symptoms of imminent death:

- Difficulty in swallowing
- Comatose or semi-comatose
- Unable to take more than sips of water
- Sleeping for long time
- Death rattle (jangle noise present in inspiration and expiration)
- Profound weakness and weight loss (asthenia / cachexia)
- Increasing drowsiness
- Difficulty concentrating and sometimes confusion
- Increasing time spent in bed and dependency on others
- Progressively falling blood pressure and /or temperature
- Poor peripheral perfusion
- Cheyne - Stokes breathing pattern
- Loss of interest in surroundings / family

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

PRINCIPLES FOR BEST CARE OF THE DYING PERSON

- Pain and symptom should be managed even if he/she is unconscious
- Keep only the essential medicines after reviewing all the drugs and avoid unnecessary interventions such as IV fluids, ARVs, antihypertensive. Care providers shall maintain presence and talk 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, religious and cultural customs in a developmentally appropriate manner.
- Palliative care practice shall be guided by the medical-ethical principles of autonomy, beneficence, non-maleficence and justice
- Important and drugs and equipment used to treat patients at the end of life may include analgesics, antiemetic, anxiolytics, antisecretory
- After death, ongoing support for the family / careers and respectful, dignified care of the body
- Need for artificial hydration and nutrition needs to be reviewed on a regular basis and were felt to be unnecessary, the reasons discussed with the patient and family.
- Any investigations at the end of life should have clear and justifiable purpose
- Clinical interventions should be reviewed in the best interest of the patient
- There should be a regular review of the hydration needs (start / continue /Stop?) and nutritional needs (start / continue / stop?)
- Care providers shall be honest, attend to emotional responses and spiritual needs.

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

Table 8: Care Suggestions for the Family When Death is Imminent

COMMON PROBLEMS AT THE END-OF LIFE

Pain and other common symptoms are mentioned at above topics and refer to the topics there.

Agitation/Delirium

- Haloperidol/Midazolam: 2 to 5 mg sc, regularly up to 60 mg /24 hours
- Lorazepam: 0.5 to 2 mg repeated depending on need

"Death Rattle"

(Excessive secretions in the upper airways), Bowel Obstruction and Drooling - Antisecretory medication

Hyoscinebutyl bromide: 20 mg q6h up to 240 mg /24 hrs
Glycopyrrolate: 0.2 to 0.4 mg two to four times per day
Atropine: 0.6 mg q6h

Octreotide: 0.6 to 0.9 mg /24 hrs. (used for intestinal obstruction to reduce Volume in GIT.

*Please see specific chapters regarding treatment of relevant symptoms

- Important drugs to consider for end-of- life care include:

1. Morphine (analgesia, improving dyspnoea, antitussive effect and for Diarrheal)
2. Haloperidol (N/V and for agitation)
3. Olanzapine as an alternative
4. Midazolam for delirium and mild sedation
5. Hyoscine, (anticholinergic / antimuscarinic) useful for colic in bowel obstruction and as anti-secretory agent in death rattle.

Result of end-of-life care

- To achieve a "good death" and be treated with respect
- Emphasis on quality of life and quality of death
- Every individual has a right to a, peaceful, pain free and dignified death

Perceived components of a good death include

- Control of pain and physical symptoms
- Clear decision making by knowledgeable physician / palliative care teams
- Empowering the patient and family, considering their wishes
- Reducing fear and knowing what to expect
- Appreciating the importance of spirituality and meaningfulness at the end-of life
- Time with family, saying goodbye and resolving conflicts
- Affirming the patient as a unique, whole person

ETHICAL DILEMMAS IN END OF LIFE CARE

- Withdrawal or refusal of specific treatment,
- Nutrition and hydration,
- Sedation
- Desire for hastened death,
- Resuscitation

Withdrawal or Refusal of Specific Treatment

- The right to refuse medical interventions is now well established.
- The right to access specific medical treatment has more potential areas of conflict.
- In many countries' treatment may only be accessible for those with the resources to pay for it.
- The right to palliative care has been asserted but less than 10% of the need is being met.
- In end-of-life care, the most common issue is refusal of treatment.
  Ethically there is no distinction made between withdrawal and refusal of any medical treatment.

Nutrition and Hydration

- The literature on withholding nutrition and especially hydration has demonstrated that decrease in intake is a normal part of the dying process and does not need to result in suffering as long as good mouth care is maintained.
- Recent literature also has shown that the use of feeding tubes in nursing home patients does not significantly improve survival.

Sedation

- When all attempts to relieve suffering have been unsuccessful, the option to sedate a patient can be considered.

- Therapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family, and health care providers.

RESUSCITATION AND LIFE SUPPORT

- Cardio-pulmonary resuscitation (CPR) was developed to increase survival in acutely ill patients. Patients with advanced, chronic life- limiting conditions rarely benefit from CPR and ongoing life support.
- The use of CPR in these cases more often results in a prolongation of the dying process if even partially successful and increased suffering from trauma.
- As with all other medical interventions the patient has a right to request that CPR not be undertaken. Unfortunately, in the absence of an advance directive and do-not-resuscitate order, the default in medical institutions and emergency care is to initiate CPR.

Desire for Hastened Death

- Patients may ask their health care providers to hasten their death.
- In palliative care this is often a cry for help and the best response is to try to understand what is driving the patient to want to prematurely end their life and to remedy the problem. But in some cases, it may not be possible to relieve the suffering or the patient may have such a high need for control that they want to determine their time of death. However, euthanasia is forbidden according to Ethiopian medical ethics

COMMUNICATION AT THE END OF LIFE

- Communication is best for implementing the best end of life care.
- For detail See communication section

Chapter 8.
Grief and Bereavement

Grief is a natural human response to a significant loss primarily related to death. It is the personal experience of the sad feeling of loss.

Grief is intense and unique and two people do not grieve exactly alike. Bereavement is the state of sorrow over the death or departure of a loved one.

Complicated Grief: a general category used to define mourning that varies from the usual course in a manner that is distinguished by intensity, time or behavior. Other terms related to this are "delayed
grief", "chronic/delayed grief", "absent grief".

STAGES OF GRIEF

The response to grief may involve denial, anger, bargaining, depression and acceptance stages "We do not enter and leave each individual stage in a linear fashion. We may feel one, then another and back again, to the first one".

- Denial: a disbelief to loss and is the mechanism for overcoming the challenges related to loss. It feels "Life makes no sense. We are in a state of shock and denial. We go numb. We wonder how we can go on, if we can go on, why we should go on"
- Anger: the anger feeling is reflected on other people.
- Bargaining: a stage where there is a feeling of guilt, we negotiate about the past with God and wish to get more chances to do something better or do things in another way. "I will never be angry at my wife again if you'll just let her live."
- Depression: usual experience in response to loss and there is a feeling of depression. This can be manifested by various forms of depression such as withdrawal, low mood, and loss of interest to the environment.
- Acceptance: agreement with the situation and keep going on life. "This stage is about accepting the reality that our loved one is physically gone and recognizing that this new reality is the permanent reality. We will never like this reality or make it OK, but eventually we accept it".

Entire family can experience anticipatory grief. Can be good if draws family together and there are periods of grief mixed with contentment. Difficulty arises if there is denial of the seriousness or withdrawal from involvement. Intense distress at this time can be a risk for complicated grief. Helped by encouragement to share feelings while paying attention to material needs.

Criteria for Complicated Grief (CG):

- At least 6 months has elapsed and better to wait 1 year
- Persistent pining for the deceased
- Seriously impairs ability to function in roles and responsibility
- Symptoms of traumatization.

How to Provide Support:

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

After death:

- Allow time for the bereaved family with the dead body
- Bereaved are commonly bereft – they may benefit from guidance
- Practicalities: remove implanted devices, discuss organ donations, complete death certificate, inform other clinicians
- Sometimes a debriefing for staff is in order
  If family not able to be present, clinician helps to integrate what has happened
- There are usually 2 reactions to sudden death: stoic silence or hysteria

STEPS THAT BEREAVED CAN TAKE TO WORK THROUGH GRIEF:

- Give visible expression to grief (for most people)
- Carry out promises made to the deceased
- Seek variety and new impressions
- If can't make it on own, seek help
- Go back to work as soon as possible
- Don't make any major life decision during the period of intense mourning
- Join bereavement (Lekso) group

WAYS TO HELP THE BEREAVED

Activity: reflection, share the mourning "Lekso" activities and ceremonies in Ethiopian culture and its benefits.

- Being there with the bereaved person/s helps and most cases need simple support
- Listening in an accepting and non-judgmental way. Showing that you are listening.
- Understand something of what they are going through.
- By encouraging them to talk about the deceased.
- By tolerating silences, offering reassurance, not taking anger personally
- By recognizing that your feelings may reflect how they feel
- Identify those potentially at risk by involving the multidisciplinary team
- Note that depression is treatable
- Bereavement counseling helps
- Family therapy can be indicated
- Listening to someone crying is difficult, but important
- Don't change the subject or distract the griever
- Attend the funeral service
- Group support (Lekso)
- Regular contact with the family after the loss

Chapter 9.
Communication in palliative care

Communication is a fundamental prerequisite for healthcare professionals or palliative care teams in order to provide effective care, support, and treatment. Effective communication with patients, their families and among colleagues is a required skill to address patient needs. However, healthcare professionals demonstrate ineffective communication skills.

Both the verbal and non-verbal communication skills are required to convey serious news and messages effectively, and provide emotional and psychological support. Active listening is vital to effective communication, and following methods help to enhance listening skills:

- Greeting: be friendly and welcoming, address the patient/family by name, and give warm greetings.
- Seating arrangement: allow the patient to take his/her comfortable position in a private room. Sit next to the patient at a reachable distance without any 'barrier' (e.g. consultation table) in between, if possible.
- Ask open questions: Open-ended questions permits to provide rich data and give freedom to the patient to express thoughts freely. Example of open-ended question: How do the treatments make you feel? How could I help you?
- Active listening: Generally, in a doctor- patient communication, doctors talk more and the patients are forced to listen, unable to clear their doubts and uncertainties. In order to get more details and to develop better rapport, it is good to encourage the patient to talk about his concerns.
- Show them we are listening: The patients should get the feeling that we are listening to them by verbal and non-verbal means. This can be done by repetition, reiteration (paraphrasing) and reflection.
- Eye contact: It is a key aspect of non-verbal communication. It enhances confidence in the patient that he/she is being attentively listened to.
- Tolerate 'brief 'silence – Healthcare professionals tend to get impatient when patients slow down their narration and become silent. It has to be understood that patients can become emotional as they narrate their past and describe a sensitive event or situation. They also need time to recollect certain events as they are telling their story. If we interrupt at this time, they can forget the chain of events or conclude that we are in a hurry and may not go on to ventilate their feelings adequately.
- Avoid unnecessary interruption: When a patient's history is elicited, though questions need to be asked for clarification and details, it should not be too frequent in a way that it interrupts the flow of communication.
- Empathize & give realistic hope: Show you understand the challenges or problems that the patient is facing. Show your interest to help him/her and give realistic hope when reassuring.

Main goals of communication in palliative care:

- Build rapport between the patient, family and healthcare professionals
- To communicate medical conditions and complex information
- Provide psychological support
- Deal about medical goals and goals of care
- To address concerns and help cope with the challenges
- To help the patient and family make informed decisions

Communicating bad news

Communicating bad news (breaking bad news) is a tough task, but an important aspect of communication. It takes time, and the majority of problems frequently need to be explained as new information is shared. There is increasing evidence that communicating bad news benefits patients and their families. However, conveying bad news requires effective communication, and using protocol is crucial. The process of delivering the bad news needs to be tailored to the needs of the individual concerned. It must be done in such a manner that it reduces the impact of the bad news and facilitates understanding and acceptance. The consequences of a bad performance can lead to immediate and long-term damage to the patient and all involved.

A trained health professional who has developed rapport, involved in the care can communicate the bad news. The following six steps for Communicating Bad News are helpful to tell bad news. A 6-step protocol (SPIKES) described by Robert is generally helpful to learn the skill.

Step 1: Setting:

-Before meeting with the patient, ensure the physical environment is conducive
-Plan what will be discussed.
-Ensure the medical evidence is collected and reviewed.
- Ensure adequate time is allocated.

Step 2: Perception

-Identify who he/she wants be with him when receiving bad news
-Assess how much the patient knows already. Question might include:
-"What do you understand about your disease or condition?"
-"What other doctors told you about your disease?"

Step 3: Invitation

-Ask the patient if he/she wants to know
-How much detail does the patient want to know?
-Question may be: "Would you like me to tell you the details about your disease?"

Step 4: Knowledge

-First give a warning shot to help the patient to prepare emotionally. Giving small information.
-Share what the laboratory or imaging results show. You may say: "the result shows you have...."
-Try to be brief, sensitive and clear.
-Do not be either too abrupt or too long.
-Silence after you said it and give pause.

Step 5: Emotions

Be sensitive and help with emotional reactions. Note that listening skill plays a key role, and responds to emotional reactions empathetically. It is important to know the common emotional reactions such as shocking, disbelief, fear, guilt, blame, and learn how to respond and answer difficult questions. Acknowledge the patient's feelings. Allow and give time to the patient to express feelings. Listening and reassurance are important at this stage.

Step 6: Summary

Ask the patient if there is any question. Summarize the discussions and ensure if the patient understands what is told. The plan for ongoing care and support should be done.

Chapter 10.
Social issues in palliative care

Social care provides assistance to those dealing with long-term conditions like terminal illness, death, loss, and bereavement. Hospitals, home care, nursing homes, civil society groups, faith-based organizations, and family support agencies should all engage in social work practice related to palliative and end-of-life care.

Family health teams and social workers can provide personal, household, educational, and social care services to communities from varying cultures, ages and socio-economic status and help patients & families across the life span in coping with trauma, suicide, and death. Family health teams and social workers should also contribute in terms of bridging the social, cultural, and economic distances often found between the community and the formal health care system.

Social Care services

- Assisting with tasks of daily living
- Emotional support/companionship
- Support against stigma and discrimination
- Orphan care and child welfare
- Referring for religious/psychological support
- Assistance for financial crisis
- Assistance for physical needs
- Informational support
- Bereavement and end of life care
- Facilitating partners support
- Psychosocial support
- Support against cultural influences

Social support network: includes a network of health care professionals, including social workers, family members, neighbors, religious groups, edir, ekub, friends, charities and volunteers who support and assist the patient with different care tasks.

Major tasks of social care provider:

- Assessment of needs for care,
- Coordinating care,
- Providing counseling and psychotherapy,
- Intervening in client crisis situations (financial & social)
- Educating patients and families about their treatment plan and the resources and support systems available to them
- Advocating for the patient,
- And coordination of a social support network system.

Integration of social services

The absence of social support is associated with poor patient satisfaction and poor quality of life. Because of lack of resources it is very hard to deliver social care in our settings; therefore, it is crucial to explore several governmental and non-governmental organizations at the community and primary care level for the purpose of determining if social care is included in their programs and for the purpose of integration with their services. It is necessary to mobilize resources from all social support networks to deliver the needed social care service. It is also crucial to work with the community itself and other traditional community organizations like edir to deliver social care.

Everyone involved in providing care for patients and their caregivers at the primary level should be aware of the organizations (Charities, sub city/woreda admin office.....) that can provide resources for social care and have task-sharing agreements in place. The social support network members who are providing the necessary care may get overwhelmed if coordinated task-sharing activities are not made.

Chapter 11.
Care for caregiver

Both the health and family caregivers are involved in giving care to the patient. Caregivers often handle many issues and neglect their own health and life. There should be a way of balancing patient, family, and personal needs. Prolonged engagement of caring for patients in home impacts the caregivers' emotionally, causing psychological distress and physical tiredness. Emotional exhaustion, loss of interest, fatigue, insomnia, significant social impairment are symptoms of burnout.

It is important for healthcare professionals to assess the careers for distress and exhaustion and provide support as necessary

- Healthcare providers can support family caregivers by various means of nursing care, symptom control, emotional support, grief support, providing information, and listening to the family's problems.
- Encourage the family members and acknowledge their good job.
- Do not blame for a mistake that is committed and be supportive to help.
- Help the family member to develop basic skills for caring at home level.

Healthcare professionals

It is also important for healthcare professionals to assess the team for distress, exhaustion and burnout and provide support as necessary. You can form a team to support each other. A regular team meeting is important to share your feelings, worries and burdens. Multidisciplinary team approach helps to reduce the burden.

Accept you can only change things within your control and cannot fix all problems.
Set a realistic goal
Do not continuously work without break, so take leave regularly
Do regular exercise

Chapter 12.
Ethical issues in palliative care

'Ethical issues in palliative care center on decisions that ensure our care will be guided by moral values that will enable us to satisfy the criteria for a peaceful and dignified death'. (Bureraet al. 2004). The four fundamental principles of medical ethics are

Autonomy acknowledges each patient's right to self-determination, without prejudice. It recognizes the right and ability of an individual to make decisions for themselves, based on their own value system, beliefs and life-span.

Beneficence: means the production of benefit, doing good and always acting in the best interests of the patient. This requires that the health care team prevents or removes harm, while doing or promoting good. It is the most commonly used principle in the application of care. Beneficence includes being honest with patients, which in nearly all circumstances will be to the patient's benefit.

Non-Maleficence: means not being malicious; not doing harm. It supposes that 'one ought not to inflict harm deliberately'

Justice relates to fairness in the application of care. It implies that patients receive care to which they are entitled medically and legally. Justice can be translated into 'give to each equally', 'to each according to need' or 'to each his due'. This means that care provision should not be based on wealth, class, creed or color.
Though these principles are undisputed, often conflicting situations can occur. For example, autonomy would be limited in the following situations
The decision-making power will automatically pass on to the next of kin if

-The person has limited cognitive or communicative ability.
-A person does not want to exercise his autonomy.

BASIC REQUIREMENT IN ETHICAL MEDICAL PRACTICE

Respect: Every human being is superior to each one of us in some way and deserves our respect. This is often forgotten because the patient has been weakened physically, emotionally and socially by the disease while the doctor and nurse have the power of the medical system behind them. Wherever there is power there can be a tendency to abuse it.

Confidentiality: Except when legally bound, the medical system has the responsibility not to disclose any personal information concerning the patient with others.

Non-judgmental approach: It is unacceptable to label anyone "a good patient" or "a bad patient". Whether the patient is thankful or ungrateful, pleasant or grumbling, we have the duty to do our best.

Informed consent: Ordinary everyday procedures, as for example injections, do not warrant a separate consent. The very fact that the patient is willing for treatment offers "deemed consent". But for any interventions beyond the routine, say for example a peritoneocentesis, a nerve block or a surgical procedure, informed consent is necessary. "Informed" is taken to mean that the patient is given essential and relevant information and has the opportunity to clear doubts.

List of Ethical Dilemmas

- Withdrawal or refusal of specific treatment,
- Nutrition and hydration,
- Sedation
- Desire for hastened death,
- Resuscitation

In every-day practice, there are bound to be situations, where what is ethically right seems doubtful. There can also be situations like one ethical principle, say autonomy, violates another, as for example non-maleficence or justice. In such situations when discussions within the team and discussions with the patient and family do not result in a satisfactory resolution of the dilemma, the matter may have to be dealt with by an "institutional ethics committee".

Chapter 13.
Referral and networking system

In order to assure the continuity of care, the city administration has a referral network from the Primary health care unit to the tertiary level of care based on the health tier system in the country. The existing referral network can be used for the program.

All Providers: Transfer notes/referral sheets should be documented during transfers between different care settings. These handovers should include:

- Summary of active symptoms issues during the admission
- Latest blood and/or imaging results (where applicable)
- Information regarding medications such as rationale for drugs used; response to medications; side effects and tolerability; date of dose adjustments
- Latest discussion/decisions on goals and extent of care
- Advance care planning discussions (where applicable)
- Possible red flags on a case-by-case basis such as complicated family issues, collusion, delay in diagnosis or treatment, etc

N.B. For unplanned emergency admissions to hospitals, inpatient hospice and home care teams (FHT) should inform hospital palliative care teams to follow-up. Conversely, discharges known to hospital palliative care teams should be handed over to community palliative care teams (FHT) to ensure continuity of care.

Networking between facilities has been developed by the city administration. Hospitals are expected to support and capacitate the primary care units and work in collaboration with other facilities. The EPAQ/EHAQ platform is a good example in the context of networking as well as hospital - health center alliance and catchment meetings.

Responsibilities of palliative care providing facilities

Specialized Hospital

- Offering tertiary palliative care services
- Provide in service training and mentorship
- Network with other primary health facilities for referral
- Keep appropriate records and compile monthly reports
- Adhere to guidelines in the management of palliative care patients

General Hospital/Primary hospitals

- Integrated palliative care service provision (in-patient and out-patient)
- Have a mechanism in place that facilitates referral for specialized palliative care needs.
- Establish a mechanism of referral linkage with other facilities in their catchment areas and community palliative care services.
- Keep appropriate records and compile monthly reports which shall be submitted to the district coordinator

Health Center/Clinics

- Serve as a frontline team within the health system for integrated palliative care service provision (community and outpatient)

- Have mechanism in place that facilitates referral for specialized interventions for control of complex pain and/or other symptoms
- Supervise health extension workers and Family health teams regarding the palliative care services

Family Health Team

- Interface between palliative care in PHC and the community by health extension workers
- Advice, support, education to patients, families and communities
- Screening, Case detection linkage and referral

Chapter 14.
Monitoring and evaluation

Monitoring and evaluation (M&E) is an action-oriented and pre-planned management tool that operates on adequate, relevant, reliable and timely collected, compiled and analyzed information on program objectives, targets and activities. Monitoring and evaluation shall be used as an advocacy tool for use of evidence-based decision making. Monitoring shall be conducted at all levels using appropriate indicators (both at facility and home settings). This framework is designed to follow and evaluate the quality of primary health care's palliative care service.

	Improving Service Access
1	§ Percentage (%) of palliative patients seen by the FHT in their home Numerator: Number of patients given PC service by the FHT at their home Denominator: Total number of patients seen by the FHT at their home
2	§ Percentage (%) of palliative patients screened for pain with screen tool at home (FHT) Numerator: Number of palliative patients visited whom was screened for pain at home Denominator: Total number of clients visited at home
3	§ Percentage (%) of palliative patients linked to PC unit after screening done at home Numerator: Number of clients screened linked to PC unit Denominator: Total number of clients screened for pain at home
4	§ Percentage (%) of patients seen at inpatient/outpatient of facility (Palliative care unit) Numerator: Number of patients who was given PC service at IPD/OPD Denominator: Number of patient who was given PC service at IPD/OPD

Please refer tool 8 for palliative care outcome scale

Responsibilities of Monitory bodies

Regional Health Bureaus

- Lead and coordinate the overall palliative care activities at regional level
- Ensure that basic palliative care medications are available at different levels of the health care delivery system
- 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

Sub city Health Office

- Overall managing and coordinating the operation of palliative care services in the PHCU- in health centers and community level
- Advocacy on palliative care to the community.
- 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.

Reference

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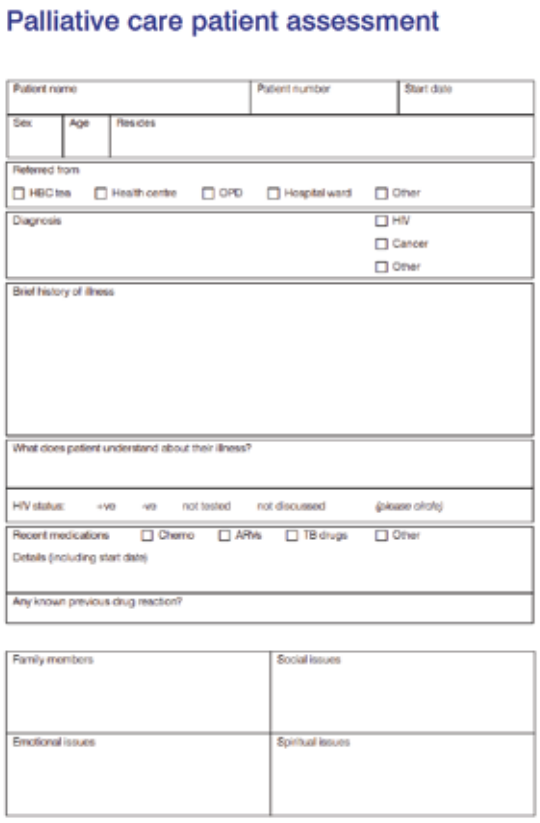
- Beating Pain, 2nd Ed. APCA (2012)
- Ethiopian federal ministry of health palliative care guideline
- Introductory Palliative Care Course for Healthcare Professionals (Uganda); PCAU/MOH (2013)
- The European Society for Clinical Nutrition and Metabolism (ESPEN): ESPEN provides guidelines and recommendations on nutrition support in various clinical conditions, including palliative care. Their publications and guidelines can be accessed through their website: https://www.espen.org/
- The National Hospice and Palliative Care Organization (NHPCO): NHPCO offers resources and educational materials on various aspects of palliative care, including nutrition.
- The World Health Organization (WHO): The WHO has publications and guidelines on palliative care and supportive care.
- Kubler-Ross E, Kessler D. On Grief and Grieving: Five Stages of Grief. J Natl Med Assoc. 2005;98(6):233.https://scholar.google.fr/scholar?q=Kubler-Ross+2005&btnG=&hl=fr&as_sdt=0,5#0

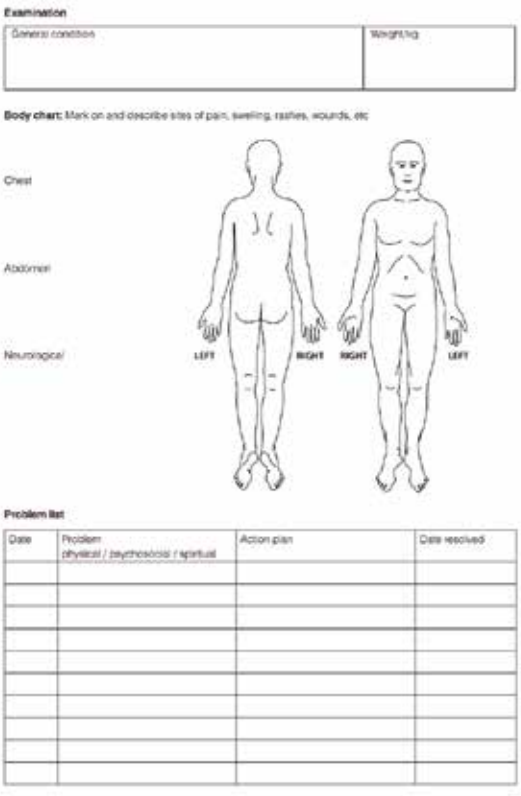
Annex

Table: Indicates types of pediatrics palliative care need patients

Population	Examples
Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Children with chronic life-threatening conditions that may be cured or controlled for a long period but that may also cause death	Malignancies, multidrug-resistant tuberculosis, HIV/AIDS
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal muscular atrophy, Duchenne's muscular dystrophy
Children with severe neurologic conditions that are not progressive but may cause deterioration and death	Static encephalopathy, spastic quadriplegia, spina bifida
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Family members of a fetus or child who dies unexpectedly	Fetal demise, hypoxic-ischaemic encephalopathy, overwhelming sepsis in a previously healthy child, trauma from motor vehicle accident, burns, . . .

Sources: Downing et al. 2016 *(29)*; Wood et al. 2010 *(30)*.





Tool 1: Source of Hospice UK toolkit 2016

Tool 2: Source of Hospice UK toolkit 2016

Home visit record for care providers

PATIENT NUMBER	DATE	PATIENT NAME	LOCATION	VISITED BY	MAIN PROBLEMS	CARE GIVEN A B C D E F G H I J	OTHER NOTES (PSYCHOSOCIAL, SPIRITUAL ISSUES)

CARE GIVEN: A BATHING, B TURNING, C PRESSURE AREA CARE, D FEEDING, E MOUTH CARE, F TOILETING, G WASHING, H SUPERVISION OF MEDICINES, I PASSIVE AND ACTIVE EXERCISES, J DRUGS PROVIDED (SPECIFY WHICH)

Tool 3: Source of Hospice UK toolkit 2016

Referral to palliative care team

Address of palliative care team: _____

_____ Phone: _____

Referral made by:

_____ Date: _____

Contact details of person/organisation making referral:

Name of patient:

Address/directions/contact details for patient: _____

_____

Nearest health facility to patient's home: _____

Age Sex Main carer:

Diagnosis:

Patient aware of diagnosis Y/N Carer aware of diagnosis Y/N

Main problems: _____

_____

_____

Current treatment: _____

_____

_____

Reason for referral:

Advice on symptom management ☐ Counselling ☐

Take over care ☐ Shared care ☐

Signature: _____ Print name: _____

Tool 5: Source of Hospice UK toolkit 2016

PATIENT NO. _____	POSSIBLE RESPONSES	Visit 1 DATE _____	Visit 2 DATE _____	Visit 3 DATE _____	Visit 4 DATE _____
ASK THE PATIENT					
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (no pain) - 5 (worst/overwhelming pain)				
Q2. Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	0 (not at all) - 5 (overwhelmingly)				
Q3. Have you been feeling worried about your illness in the past 3 days?	0 (not at all) - 5 (overwhelming worry)				
Q4. Over the past 3 days, have you been able to share how you are feeling with your family or friends?	0 (not at all) - 5 (yes, I've talked freely)				
Q5. Over the past 3 days have you felt that life was worthwhile?	0 (no, not at all) - 5 (Yes, all the time)				
Q6. Over the past 3 days, have you felt at peace?	0 (no, not at all) - 5 (Yes, all the time)				
Q7. Have you had enough help and advice for your family to plan for the future?	0 (not at all) - 5 (as much as wanted)				
ASK THE FAMILY CARER					
Q8. How much information have you and your family been given?	0 (none) - 5 (as much as wanted) N/A				
Q9. How confident does the family feel caring for ____?	0 (not at all) - 5 (very confident) N/A				
Q10. Has the family been feeling worried about the patient over the last 3 days?	0 (not at all) - 5 (severe worry) N/A				

Tool 7: - Source Africa Palliative Care Outcome Scale

Community care volunteer kit

Basic contents

- Plastic gloves
- Plastic sheeting
- Plastic bags
- Soap
- Washing powder
- Plastic bottle to use for incontinent patients
- Pieces of clean cloth for cleaning wounds
- Clean dressings
- Sticky tape
- Vaseline
- Gentian violet paint
- Paracetamol tablets
- Aspirin
- Laxatives (eg bisacodyl tablets or suppositories)
- Oral rehydration salts
- Metronidazole tablets (crushed) for putting on wounds
- Home visit record sheet
- Patient-held record to leave with patient
- Pen

Health worker kit

If the kit is to be carried by a health worker, some extra things can be added, such as:

- Ibuprofen
- Codeine*
- Morphine*
- Amitriptyline
- Diazepam
- Metoclopramide
- Amoxycillin
- Cotrimoxazole
- Metronidazole
- Ketoconazole
- Catheters
- Drug dosage lists
- Patient assessment form

* National regulations about the storage and carrying of controlled drugs must be followed.

Tool 4: Source of Hospice UK toolkit 2016

Pain assessment tool

Choose the pain score that is most helpful for your patient.

Five-finger score

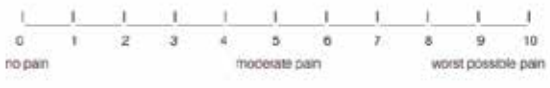
Ask the patient to show how bad the pain is with their hand

Faces score

Ask the patient to point to the face which shows how bad their pain is

Number score

Ask the patient to show where their pain comes on the scale of 1–10



Eight important questions to ask the patient

- **Where** is the pain? (there may be more than one pain)
- **When** did it start?
- **What** effect does the pain have on life/work/sleep
- **What** does it feel like? (eg stabbing, cramping, burning, etc)
- **Timing** – Is the pain there all the time or does it come and go?
- **Treatment** – Has any treatment been tried and has it helped?
- **Changing** – What makes it better or worse (eg movement, eating, time of day, etc)?
- **Causing** – What do you (the patient) think is causing the pain?

Tool 6:- Source of Hospice UK toolkit 2016