

# Basic Certificate Course in Palliative Medicine

Manual for a Six-Week Training Program in  
Palliative Care for Doctors



**INSTITUTE OF  
PALLIATIVE MEDICINE**



WHO Collaborating Centre for  
Community Participation in  
Palliative Care and Long Term Care



*Sri Aurobindo Society*

**SANJEEVAN**

AN INTEGRAL APPROACH TO END-OF-LIFE CARE

## **SANJEEVAN Palliative Care Project**

(A joint venture between Sri Aurobindo Society and  
Institute of Palliative Medicine)

Supported by a project grant from Tata Social Welfare Trust



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## **Basic Certificate Course in Palliative Medicine**

March 2022

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# 1

## Introduction

People with life-limiting diseases including cancer and other life threatening ailments, have pain and other difficult symptoms including psychosocial and spiritual distress. This can dramatically decrease quality of life of the patient as well as place a burden on the family's economy and health care system. This is the same for most of the elderly towards the end of their life.

Palliative care improves the quality of life of people with life-threatening or debilitating illness by providing relief from pain and other physical symptoms and addressing psychosocial and spiritual needs. To ensure the most effective care for patients, palliative care begins at the point of diagnosis, continues throughout treatment, and bereavement support is offered to the family after the patient's death. When cure is possible, palliative care provides essential care to relieve pain, control symptoms, and minimize suffering.

Palliative care has not been adequately covered in undergraduate or post graduate medical education. There have been considerable developments in this area globally over the last few years. Still these initiatives have been able to address only a minor fraction of patients in need of care. One of the major areas which need urgent attention is the capacity building. But there are only a few organized, structured regular training programs in palliative care in low and middle income countries.

The majority of patients in need of palliative care are currently looked after by health care professionals without formal training in palliative care. The Basic Certificate Course in Palliative Medicine is aims at helping doctors to consolidate and develop their confidence and expertise in palliative care. The course is designed also to introduce the subject to health care professionals who wish to develop specialist palliative care knowledge and skills in future.

# 2

## **Suggested Core Competencies in Palliative Care for a Doctor at the Primary Level**

1. Should be able to identify patients in need of palliative care.
2. Should be able to assess, diagnose and manage physical symptoms in patients with advanced diseases.
3. Should be able to offer emotional support to patients with advanced diseases and their families.
4. Should be able to identify complex emotional problems and difficult physical symptoms requiring referral to specialist.
5. Should be able to link up patients with possible social support system when necessary.
6. Should be able to assess spiritual needs of the patient and refer if necessary.

# 3

## Curriculum for the Six-Week Course

### Course Outline

- The Basic Certificate Course in Palliative Medicine has six weeks of interactive tutorials, bed side clinical sessions, written assignments and skill development.
- There will be clinical placement for thirty-two days in out-patient service, in-patient ward and home care services.
- As part of the course, the candidate must submit 10 case histories, four written assignments and one project.
- There will be an evaluation at the end of the course. Successful candidates will be awarded a certificate.
- Type of Course : Offline or Hybrid(300 Hours)
- Duration : 6 Weeks (42 days)

### TIME ALLOCATION

- Theory sessions : 10 days (60 hours )
- Clinical Practice : 30 days (240 hours)
- Examination : 02 days (10 hours)

## AIM

### Aim of the course

The course aims to:

- Provide the candidate with an opportunity to develop relevant clinical skills and theoretical knowledge in palliative care. Particular attention will be paid to the holistic, patient and family centered nature of palliative care.
- Develop the ability to practise evidence-based clinical care in the light of improved knowledge, newer skills and personal reflection.

### Learning objectives

At the end of the course, the participants should be able to attain necessary skills and knowledge in the following areas:

- **Patient care:**
  - Be able to evaluate and provide holistic care to patients with incurable and life limiting illnesses.
  - Be able to develop a basic treatment plan for patients with common symptoms associated with life-limiting illnesses.
  - Be able to identify indications for transferring patients to the inpatient palliative care facility.
- **Medical Knowledge:**
  - Acquire basic knowledge of the following topics:
    - Symptom evaluation and management:
      - Pain
      - Dyspnoea
      - Constipation and diarrhea
      - Nausea and vomiting
      - Palliative care emergencies
    - End of life care

- Spirituality
- Medical ethics
- Palliative care for elderly and children
- Communication
- Nursing issues

## **Theory sessions (60 hrs) organised under eight modules**

### **Module 1 # Introduction to palliative care:**

- Introduction to palliative care
- Communication skills
- Ethical issues
- Spirituality in palliative care

### **Module 2 # Management of pain:**

- Definition and pathophysiology of pain and concept of ‘total pain’
- Classification and assessment of chronic pain
- Features of neuropathic pain
- History and development of the analgesic ladder
- WHO guidelines for cancer pain management
- Routes of drug administration: Use of subcutaneous route when oral medication not possible

### **Module 3 # Management of other Symptoms:**

- GI Symptom management (Nausea & Vomiting, Constipation, GI Obstruction)
- Respiratory symptom management (Dyspnoea)
- Psychological issues in chronically ill patients

## **Module 4 # Palliative care emergencies**

- Spinal cord compression
- Superior vena caval obstruction
- Bleeding
- Hypercalcemia
- Delirium
- Severe pain

## **Module 5 # Palliative care for children, elderly & patients with non-malignant diseases**

- Palliative care for children
- Palliative care for elderly
- Palliative care for patients with non-malignant diseases

## **Module 6 # Nursing issues**

- Wound care
- Stoma care
- Care of bedridden patients
- Lymphoedema care and massage demonstration
- Homecare & home care protocol

## **Module 7 # Organization of palliative care**

- Setting up palliative care centers at hospitals and primary health centers
- Palliative home care programs- role and functioning
- Community participation in palliative care



## **Module 8 # The Last 48 Hours of Life**

- Symptom control at end of life
- End of life communication
- Ethical issues in relation to end of life care
- Terminal care at home and in-patient set up

## **Contents of training modules**

### **Module 1. Introduction to palliative care**

#### **a) Introduction to palliative care**

- **Learning objectives**

By the end of the session, the participant should be able to

- Understand the concept of “total care” in chronically ill patients.
- Understand the definition of palliative care and different terminologies associated with palliative care
- Understand the concept of Quality of Life (QOL) and factors that may affect QOL.
- Understand how issues of chronically ill differ from those of acutely ill and the need for their regular support.
- Understand the concept of multidisciplinary team work and why other professionals and non-professionals need to be involved in the care.
- Understand the need and benefits of training in palliative care and how the training could help in their own clinical practice.

- **Topics to be covered**

- i. History, definition and scope of palliative care.
- ii. The concept of total care.
- iii. The concept of QOL
- iv. The issues of chronically and incurably ill persons
- v. Role of a medical professional as a member of the palliative care team.

## **b) Communication skills**

- **Learning objectives**

By the end of the session the candidate should:

- Understand the importance and need of effective communication in medical practice
- Learn the basic skills in communicating honest information with a patient in a sensitive manner
- Learn the strategy for breaking bad news and handling the responses
- Be aware of the context and complexity of communication
- Handle communication issues like collusion and denial in a nonjudgmental manner
- Learn the principle of active listening
- Identify the barriers in communication

- **Topics to be Covered**

- i. Basics of communication – verbal and nonverbal behaviors
- ii. The context and complexity of communication
- iii. Breaking of Bad News
- iv. Effective communication
- v. Basic listening skills
- vi. The barriers/ distancing tactics
- vii. Collusion and denial
- viii. How to communicate a crucial information to a patient
- ix. Handling the reactions and responding to difficult questions
- x. Role plays addressing above issues

## **c) Ethical issues in palliative care**

- **Learning objectives**

At the end of the session the participant should be

- Able to understand basic principles of medical ethics
- Able to apply medical ethics in palliative care practice

- Aware of ethical dilemmas in palliative care practice
- **Topics to be covered**
  - i. Cardinal principles of medical ethics
  - ii. Autonomy and confidentiality
  - iii. Attitude of health professionals and personal motivation

**d) Spirituality in palliative care**

At the end of the session the participant should

- Be aware of the diverse ways in which spirituality is perceived and practised
- Be aware of tools for assessment of spiritual pain
- Be aware of guidelines for addressing spiritual issues

**Module 2. Management of pain**

● **Learning objectives**

At the end of the session the participant will be able to

- Understand the need for proper assessment and management of pain
- Understand the definition and pathophysiology of pain including the concept of total pain
- Assess and manage pain as per WHO guidelines on pharmacological management of cancer pain
- Know the drugs commonly used in WHO analgesic guideline in terms of dose, dosage, route of administration, side effects and contraindications.
- Learn the principles governing the use of Morphine
- Write an appropriate prescription for patients with chronic pain following the WHO analgesic guideline.

● **Topics to be covered**

- Definition and pathophysiology of pain and concept of ‘total pain’
- Classification and assessment of chronic pain
- Features of neuropathic pain
- WHO analgesic ladder

- WHO guidelines for cancer pain management
- Routes of drug administration: Use of subcutaneous route when oral medication not possible

### **Module 3. Management of other physical symptoms**

By the end of the session the candidate should be able to:

- Identify the causes and plan the management for a patient with common gastrointestinal and respiratory & other symptoms
- Recognize common psychological problems and plan the management accordingly

#### **a) Gastrointestinal symptoms in advanced disease – Nausea, Vomiting, Intestinal Obstruction, Constipation**

- **Learning objectives**

At the end of the session the candidate will be able

- To understand that gastrointestinal symptoms commonly occur in patients with advanced disease like cancer
- To understand that the symptoms can be due to various causes and mechanisms operating both within and outside the gastrointestinal system
- To learn the etiology and management of gastrointestinal symptoms
- To learn the stepwise guidelines in using antiemetic and other drugs to control nausea and vomiting
- To assess treatment related side effects

- **Topics to be covered**

- i. Pathophysiology underlying the GI symptoms,
- ii. Understanding the mechanisms
- iii. Management
- iv. Complications

## **b) Management of respiratory symptoms in advanced diseases**

- **Learning objectives**

At the end of the session the candidate will be able

- To understand that respiratory symptoms are common in any advanced disease
- To understand that etiology could vary from bronchopneumonia, lung metastasis or mediastinal syndromes to pleural effusions or varying lung pathologies
- To understand correctable and non-correctable causes
- To understand that simple logical measures like various drug combinations, nebulization, bedside chest physiotherapy or a procedure like pleural tap or intercostal drainage can be of tremendous benefit and improve quality of life of patient.

- **Topics to be covered**

- i. Dyspnoea definition, types, causes of breathlessness in advanced cancer
- ii. General principles of management of dyspnoea
- iii. Role of opioids and corticosteroids in respiratory distress
- iv. Role of Oxygen in breathlessness
- v. Respiratory panic attacks
- vi. Bed-side procedures in management – pleural tap, ascitic tap, intercostal drainage
- vii. Management of dyspnoea at home

## **c) Psychological issues in chronically ill patients:**

- **Learning objectives**

At the end of the course candidate will be able to

- Display knowledge and understanding of psychological responses to illness in a range of situations, and skills in assessing and managing these in practice

## Module 4 . Management of palliative care emergencies

### Emergencies in palliative care:

- **Learning objectives**

At the end of the session the candidate will be able

- To understand the clinical features and differential diagnosis in common emergencies in palliative care
- To learn about the investigations that may be relevant
- To learn the interventions available, their benefits and burdens

- **Topics to be covered**

- i. Spinal cord compression
- ii. Superior vena caval obstruction
- iii. Bleeding
- iv. Hypercalcemia
- v. Delirium
- vi. Severe pain

## Module 5. Palliative care for children, elderly & patients with non-malignant diseases

- **Learning Objectives**

At the end of the session the candidate will be able to

- Inculcate knowledge and skills required to identify, manage and refer children with chronic / life threatening illness.
- Understand the manifestation and course of age associated impairments common in old age, in order to identify appropriate plans of management.
- Describe different clinical manifestations and disease processes that are life limiting, and understand different barriers to offering care services to these conditions.

- **Topics to be covered**

- Palliative care in children

- Palliative care in elderly
- Palliative care in non- malignant conditions

## **Module 6. Nursing issues in palliative care**

- **Learning objectives**

At the end of the session the candidate will be able to

- Inculcate knowledge and skills required to identify, manage and refer problems in need of specific nursing interventions during the course of palliative care

- **Topics to be Covered**

- Pressure sores
- Wound care
- Stoma care
- Care of bedridden patients
- Lymphoedema care and massage demonstration
- Routes of drug administration: Use of subcutaneous (SC) routes when oral medications are not possible

## **Module 7. Organization of palliative care**

- **Learning objectives**

At the end of the session the candidate will be

- Aware of the barriers and methods to establish palliative care at specialist hospitals and primary care level
- Able to know about the role and functions of palliative home care services
- Aware of the scope of community participation in palliative care

- **Topics to be covered**

1. Setting up palliative care centers at hospitals and primary health centers
2. Palliative home care programs- role and functioning
3. Community participation in palliative care

## **Module 8. The last 48 hours of life**

- **Learning objectives**

At the end of the session, the participants will be able to

- Recognize the terminal / dying phase
- Communicate regarding the death and dying with the family
- Assess and manage physical, psychological and spiritual issues of the patient
- Provide care giver support
- Withhold and withdraw unnecessary interventions
- Plan and coordinate care

- **Topics to be covered**

- Physical problems at end of life and it's management



## EVALUATION

Evaluation will be based on theory examination, evaluation of case histories, and written assignments. By the completion of the six weeks, each candidate has to submit 10 case histories, four written assignments and present one project.

Minimum 50%marks need to be scored for a pass. The candidate has to score a minimum of 50% separately for theory examination, case histories, written assignments and project presentation.

The total marks of the examination will be 500.

<b>Modality of the exam</b>	<b>Total Marks</b>	<b>Category</b>	<b>Marks Distribution</b>
Written (Descriptive)	100	Short questions – (10 out of 12)	(10 x 10)
OSCE	90	10 stations	
Clinical case presentation	100		
Project presentation	100		
Assignments	100	4 Assignments	(25 x 4)
Log Book maintenance	10		
Total	500	Per class = 0.278	

# 5

## Background Material

### Module 1: Introduction to palliative care

#### Module 1a : Philosophy, principles and scope of palliative care

- **Palliative care:**

Palliative care is an attempt to prevent and manage suffering especially when the condition is incurable and progressive. By compassionate approach, it provides active total care to improve the quality of life of patients as well as their families. It can be provided at home, health centers, hospitals and hospices by a multidisciplinary team involving healthcare professionals and volunteers.

#### **WHO 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 and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual<sup>1</sup>.

#### **Different terminologies:**

For historical reasons, the term ‘hospice care’ is generally understood as terminal care although hospices now provide a much wider spectrum of care in many countries. It is now most often considered as synonymous with the term Palliative Care.

‘Supportive Care’, ‘Support Team’, ‘Supportive and Palliative Care Team’ and ‘Pain and Palliative Care Team’ can be presented and interpreted in different ways, starting with support for a patient in curable state to palliation when the disease is incurable.

An increasingly used term in the UK is ‘Supportive and Palliative Care’ (SuPaC). This term tries to convey the idea of the spectrum of care, physical and nonphysical, and the fact that such input can be at any stage in the disease process.

In practice, the non-curative care provided in the hospital setting, especially in Oncology Centers, is supportive and palliative care.

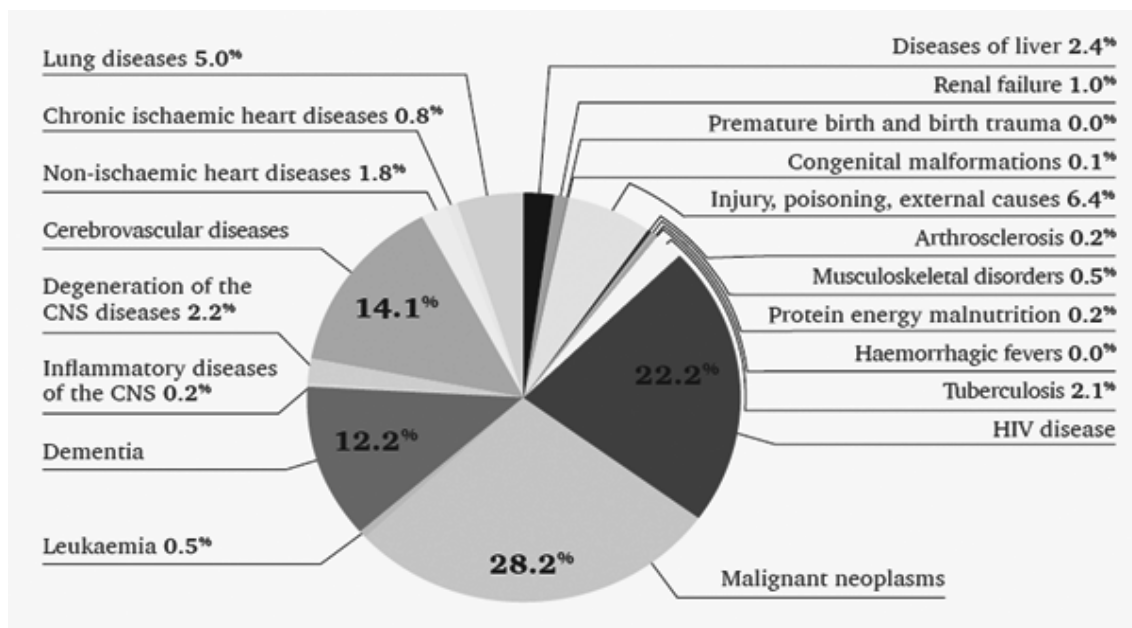
## Potential palliative conditions

- a. “The Usual suspects” – progressive life-limiting illness
  - i. Incurable cancer
  - ii. Progressive, advanced organ failure (heart, lung, kidney, liver)
  - iii. Advanced neurodegenerative illness (ALS, Alzheimer’s Disease)
  - iv. AIDS
- b. Sudden fatal medical conditions
  - i. Non reversible neurological insults like major infarcts, intracranial bleed, traumatic brain injury
  - ii. Post-cardiac arrest ischemic encephalopathy

## Scope and current status of palliative care:

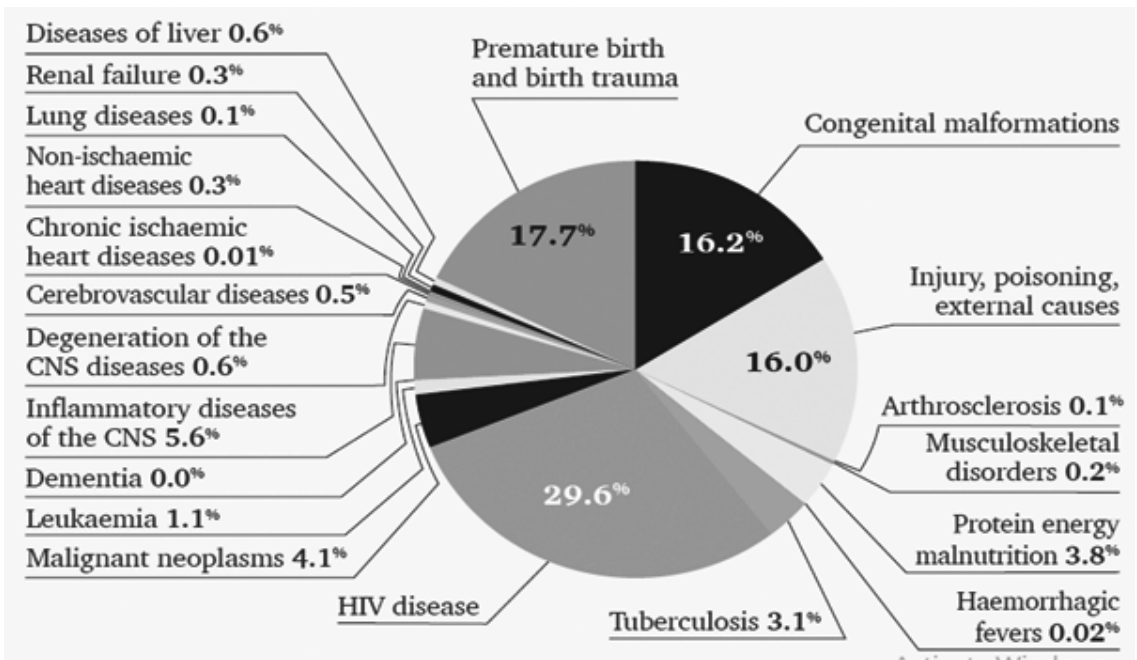
Roughly 400 persons per 100,000 population would need palliative care on an average. The need for palliative care is projected to increase significantly among the older population and patients with dementia.

Worldwide need for palliative care for adults by disease groups (Age 20+ years, 2017)

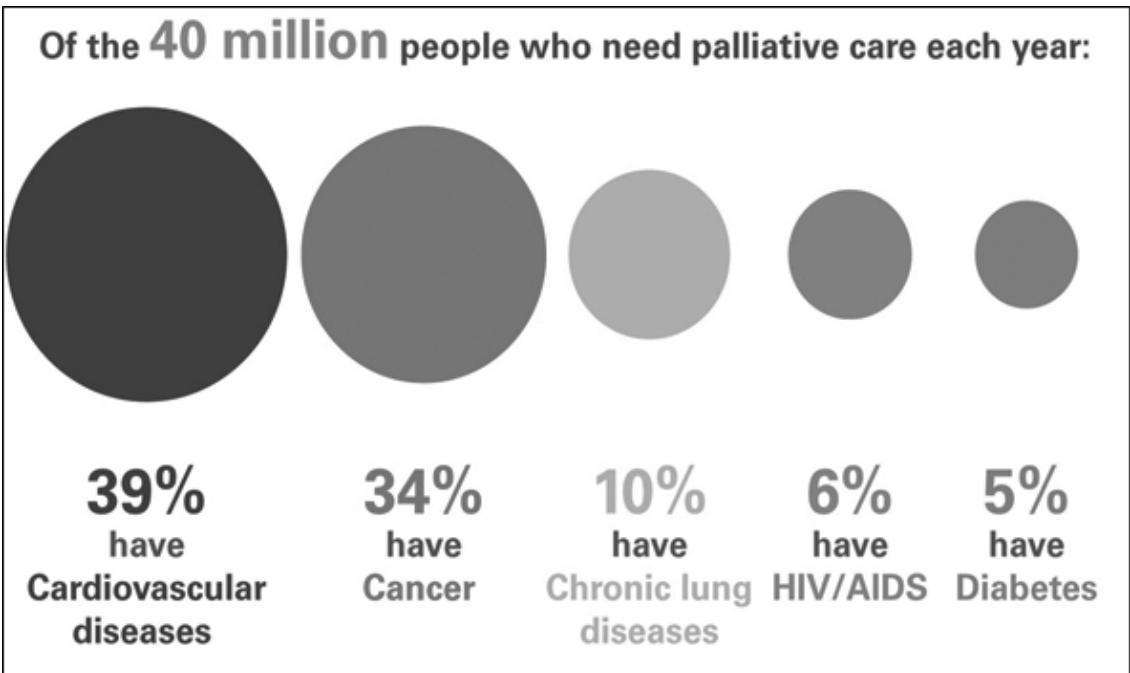


*Global Atlas of Palliative Care 2nd Edition, Oct 2020*

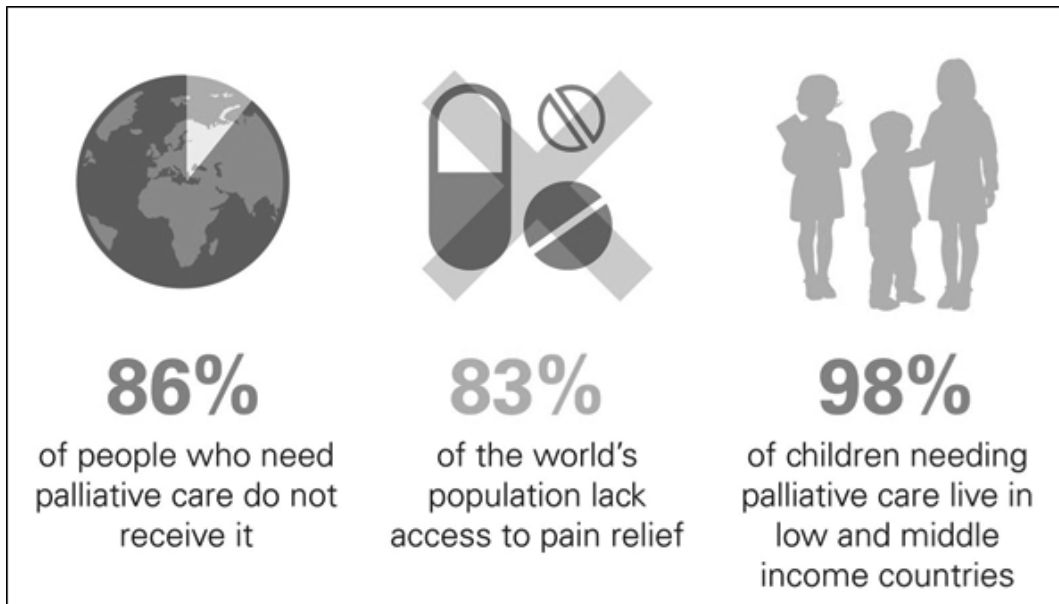
Worldwide need for palliative care for children by disease groups (Age: 0-19 years;2017)



*Global Atlas of Palliative Care 2nd Edition, Oct 2020*



Improving access to palliative care : WHO infographics \_palliative \_care

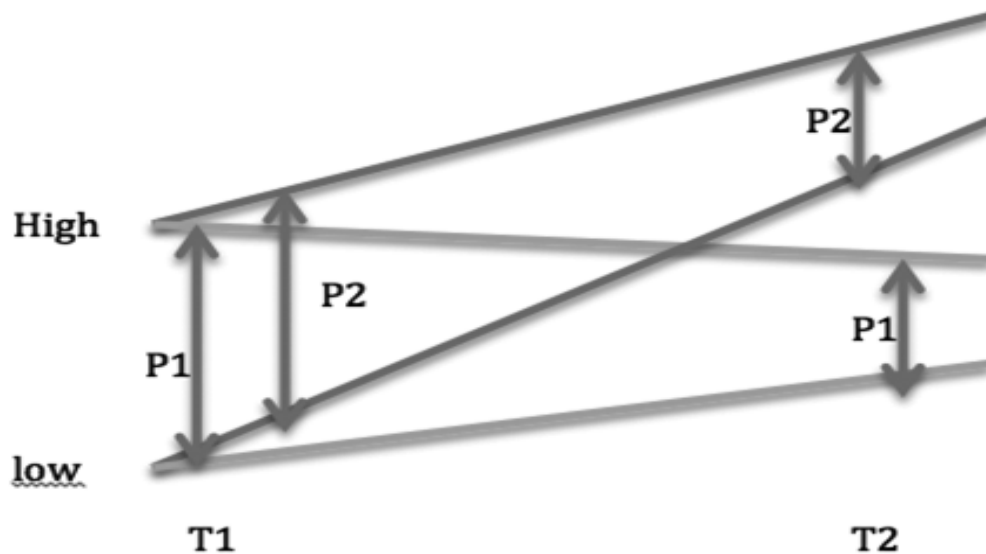


Improving access to palliative care :WHOinfographics \_palliative \_care

### Concept of Quality of Life:

The concept of quality of life can be described in different ways. It can be considered as a broad concept that encompasses how our life altogether is. It can also be considered as a specific health related concept, focusing on symptoms and level of functioning

According to Gap theory of Calman, the difference between an individuals expectations and its perception of the given situation has got an inverse relationship with the quality of life- smaller the gap , higher the quality of life. According to this theory , quality of life can be made better by either decreasing the expectations or by improving the experiences.(refer figure below)



*Figure: Gap theory of Calman*

Health related quality of life focuses on impact of a persons health on his/her quality of life. It takes into account different domains including physical, emotional, and social functioning of the individual.

## **Palliative care and Non-Communicable Diseases:**

Palliative care has become very relevant in recent years because of two reasons.

1. Non-communicable diseases (NCDs) have shown increasing impact on health status in populations globally. Of 56.4 million global deaths in 2015, 70%, were due to non-communicable diseases (NCDs)<sup>2</sup>.
2. Ageing of the population has caused the number of people in need of supportive care in the community to go up. United Nations report on ageing states that virtually every country in the world is experiencing growth in the number and proportion of older persons in their population. Population ageing is poised to become one of the most significant social transformations of the twenty-first century<sup>3</sup>.

### **Public health approach in palliative care:**

World Health Organization has been advocating for the need to promote a public health approach with integration of palliative care programme into the existing health systems, tailored to the specific cultural and social context of the target populations. The resolution WHA 67.19 of the Sixty-seventh World Health Assembly, appeals to Member States to strengthen Palliative care as a component of comprehensive care throughout the life course<sup>4</sup>. This builds on the foundation of WHO Alma Ata declaration of 1978 which highlights primary health care as essential health care based on practical, scientifically sound, and socially acceptable methods and technology ,made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford...”<sup>5</sup>



*Public Health Approach in Palliative Care*

### **Management of patients with advanced disease at home:**

It is possible to manage patients with advanced diseases at home. Establishment of affordable, accessible and quality palliative care facilities in the community will reduce hospitalization of incurable patients. This will be a welcome step as people will be at home during the end-stage of their lives. Good quality community based healthcare services will provide emotional and spiritual support for patients within their home. It can help prevent complications in bed-ridden patients. This can be done in partnership with the family/ neighbourhood/ local community who have a keen interest in wellbeing of the patient.

## **Palliative care as part of Primary Health Care:**

It is now well realised that specialist palliative care services alone will not be able to address the enormous number of patients in need of palliative care. Availability of simple effective protocols for symptom relief, a low technology approach on one hand and inability of hospitals in offering ‘Total Care’ for a patient with advanced diseases for the rest of their life make palliative care a much-needed component of Primary Health Care. As early as 1990, World Health Organization recommended that “Pain relief and palliative care programme should be incorporated into the existing healthcare systems: separate systems of care are neither necessary nor desirable” and “to ensure that equitable support is provided for programme of palliative care in the home” and that “most patients’ palliative care needs do not require specialist palliative care”.<sup>6</sup>

Primary Health Care teams have a big advantage that they know the patients in the region over long periods of time. They will also be able to identify patients from their cancer and chronic disease registers who might benefit from an early palliative care approach. Public health experiments integrating palliative care into primary health care systems have shown that cost effective good quality care is possible at the community level even in a low-income country.<sup>7</sup> This can be done in line with the spirit of the values pursued by the Declaration of Alma-Ata: social justice and the right to better health for all, participation and solidarity<sup>5</sup>

Doctors, nurses and health workers at the Primary Health Care level can easily master the skills and knowledge of symptom relief and emotional support through simple short courses/ training programs and competent agencies/ trained volunteers in the community<sup>8</sup>.

The success of the programme in terms of quality and coverage depends on the meaningful involvement of maximum number of stakeholders. Since the problems of the patient are multiple including physical, psychosocial, emotional and spiritual, it is possible to start action at any point depending on availability of the resources and build capacity in other necessary areas in a phased manner. Figure 2 represents the matrix depicting the interplay between different components of community-based palliative care services





Figure 2: Matrix of community based palliative care services

### History of palliative care:

Compassionate care for sick and bedridden has always been an agenda for human beings. Religions had a big role in evolving the care of incurably ill. Since cure was not possible for most of the diseases, ancient hospitals were basically centres of care. Buddhism had played a major role in the establishment of institution-based care for the sick, bed ridden and dying people. Teachings of Buddha in stone edicts by Emperor Ashoka dating back to third century BC clearly mentions how patients should be looked after. The concept of compassionate care outlined are very much in line with what we call Palliative care today. Buddhist Missions carried these messages of care to many regions in South East Asia along with other Buddhist traditions and practices. Institutions of care (Bimaristan) in Bagdad and Damascus in 10-12 Century were part of Islamic tradition of care

Routes of modern hospice movement in the West can be traced back to the Christian Hospices in Europe. The first European hospice was established in Rome by St Fabiola in the 4th Century. More hospices for the sick, the poor, pilgrims and crusaders were established in the Middle Ages in Europe. All of them were later closed down during the Reformation period ( 16 -17 Century).

Further development in this area happened in 17<sup>th</sup> century with the establishment of Royal Hospice in Madrid (1668) and Hospice du Calvaire in Lyon (France) which was established in 1842. Our Lady's Hospice' in Dublin was established by Irish Sisters of Charity in 1879. The first hospice in England was St Joseph's Hospice established in London in 1905. From

the late nineteenth and early twentieth century, terminal care homes and hospices were established in London, New York and several European cities as well as one Indian city (Pondicherry).

In 1967, Cicely Saunders and her colleagues opened St Christopher's Hospice, the world's first modern hospice in London, UK, where clinical care, teaching, and research were combined within an overall philosophy that was seen as a middle way between too much and too little treatment. St Christopher's became the stimulus for an expansive phase of hospice development in UK and rest of the World.

The first hospital support team for terminal care (as it was then called), was established at St Thomas's Hospital, London in 1976.

In 1987, palliative medicine was established as a subspecialty of general medicine, and later as a specialty. Similar developments happened later in Ireland, Australia, New Zealand and USA.

The WHO first formally defined the term palliative care in 1989. The definition was revised in 2002. The concept has been incorporated in various guidelines by WHO. The World Health assembly in 2014 emphasised a public health approach in palliative care and recommended that palliative care should be incorporated into all levels of mainstream health care system including Primary Health Care.

The first modern hospice in South East Asia was opened in 1962 in Colombo by Dr Rustomjee, but the institution did not last long.

In India palliative care was initiated in Gujarat in the 1980s with the opening of a pain clinic and palliative care service under the department of anesthesiology at Gujarat cancer and research center. In 1986 Professor de 'Souza opened the first hospice, Shanti Avedna Ashram in Mumbai. From the 1990s onwards there was a significant increase in the momentum of development of hospice and palliative care provision witnessed by an increase in the number of services and other key events like the formation of the Indian Association of Palliative Care in 1994.

Neighborhood Network of Palliative Care (NNPC), formed in 2001, provides an appropriate model of community-based palliative care for low-resource countries worldwide. In 2008, Kerala became the first Indian state to announce a palliative care policy. The Medical Council of India has approved a postgraduate course in palliative care and in 2012 the first Doctor of Medicine (MD) course was started in India.

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## Module 1b : Communication skills

Communication is a key part of clinical care. It can determine the patient's experience of quality of care and also health outcomes. The key components of communication includes the content (the material information exchanged), the process (sending and receiving information) and the emotional experience.

There may be a range of factors that facilitate and impede communication. These may be:

- Staff (professional) factors: Attitude, training and competence etc
- Patient factors: Tiredness, sensory disabilities, personality etc
- Situational/System factors: Time, privacy, cultural factors etc

The medium of communication is usually described as verbal and non-verbal, both of which are important for effectiveness. However, especially when sensory disabilities (hearing, vision, cognitive etc) are at play, all possible methods of communication are important (eg writing, drawing, touch, gestures & movement, sensory aids).

There are various **techniques** used for communication in clinical scenario, one of which is CLASS.

- **Context:** Ensure optimal settings to allow communication, reduce unwanted stimuli, increase comfort and support factors of patient
- **Listening skills:** Open style questions to encourage patients to tell their story. Elicit what the patient and family knows and what they expect.
- **Address Emotions:** Identify emotional responses of patient and family and manage them (empathise, validate and explore)
- **Strategy:** Explain what is the plan of care and the role for clinician, patient and family
- **Summary:** Summarise the discussion and confirm that everyone has a shared understanding

In the context of palliative care, communication is of particular relevance. This is because patients are often facing catastrophic life changes and going through difficult emotional states. In addition, a significant challenge is posed to patient and family relationships due to impact of the medical condition and normal supports and coping may not be easily available. Palliative care professional can use good communication skills to support the

patient in this life altering experience. The **purpose** of communication in palliative care can be summarised as:

- Engage patient and family in the care process
- Elicit patient's (and family's) understanding and expectations
- Educate patient and family through sharing and explaining medical information
- Emotions are carefully addressed and managed
- Enlist patient and family as active collaborators in rather than passive recipients of care

### **Context setting factors:**

- **Time:** Choose a time of day that optimises patient communication (not too tired or drowsy) and your alertness level
- **Place:** A quiet place without any interruptions and obstructions to be chosen, make sure that you are at the same eye level with the patient.
- **Persons:**
  - **Professional:** To be ready with all the background information needed. He or she should determine the agenda that is expected to be achieved. List of dos and donts.
  - **Patient:** Enquire if the patient is alone or with care giver. Make sure that the patient is comfortable to communicate and consider any need for sensory aids.

### **Listening:**

This is arguably the most important aspect of communication. The key task is to allow the patient to express themselves without constraints. The professional should be able to determine what the patient already knows and what they seek to know and their expectations. A few techniques that help in active listening are:

- Use open ended questions in preference to closed ones, especially at the beginning. Avoid leading questions.
  - Open ended questions are where the patient is able to respond in their own description E.g. Can you tell me about your pain?
  - Closed ended questions restrict the possible responses to a few that are set by the interviewer (E.g. Do you take analgesics regularly?)

- Leading questions indicate to the patient what the expected response is (E.g. After taking medications your pain would have reduced, isn't it?)
- Make use of therapeutic silence
- Respond to cues about problems and distress by clarifying and exploring them
- Avoid interrupting before patients have completed important statements
- Summarise information: This shows patients that they have been heard and allows them to clarify misunderstandings
- Use non-verbal and verbal skills for optimal effects
- **Behaviour** is what is observed, what the patient is doing eg sitting alone, smiling, laughing, crying etc.
- **Emotion** or mood is what the patient feels: common emotions universally experienced are happiness, surprise, sadness, anger, fear, disgust. These emotions may or may not be visible in facial expressions or actions of the patient. Verify with the patient whether your assessment of patient's emotion is correct eg "To me, it looks/sounds like, you feel a lot of anger/sadness/fear... but I maybe wrong"
- **Thoughts** are internal monologues in the patient's mind. When this is spoken/expressed it can be understood by others. Ask about thoughts to find out, but do not force the patient to share their thoughts. Eg "I wonder what are the thoughts in your mind these days.." "What do you think about mostly these days" "When you are alone, what are the things that come to your mind, what are the thoughts in your mind"

Emotions can affect thinking and vice versa. Logical thinking/reasoning is maximised in neutral emotional state; positive or negative emotions can reduce logical reasoning. Often, when emotions are intense, it may be difficult to have clarity about thoughts. For example we may not make the best decisions when we are very angry or extremely happy or sad.

Similarly when thinking about distressing or sad situations, we tend to feel sad; thinking that people disrespect or insult us can make us feel angry.

**Addressing emotions** in communication helps to reduce the intensity of emotions and have better understanding our thoughts.

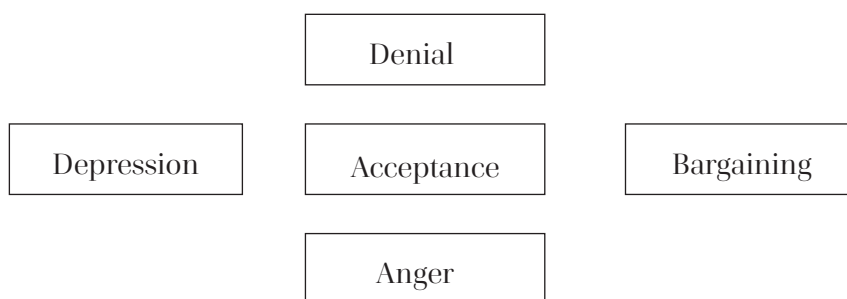
There are three steps usually recommended in addressing emotions: **EVE**

**Empathise:** This involves being able to identify the emotion that the patient might be experiencing by comparing it to our experience

**Validate:** This acknowledges patient’s right to experience the emotions, and that it is ok to feel them and share them. Eg “I can imagine this is frightening/sad for you, maybe in this situation most people might feel the same” DO NOT EVER say to the patient ‘you should not think/feel x,y,z’

**Explore:** Try to understand what circumstances and what thoughts are linked to these emotions. Eg “I wonder what are the things which have happened or thoughts in your mind that make you afraid/sad/angry”

Kubler-Ross, a Swiss-American psychiatrist carried out seminal work with terminally ill patients and described stages of coping amongst her patients. These were Denial, Anger, Bargaining, Depression and Acceptance. Over time it has been recognised as not stages in a step-wise manner, and not everyone goes through all the phases.



Depending on doctor patient relationship, there are different models that are described in breaking bad news (WHO) Individualised disclosure taking into account patient perspective is the preferred model in modern clinical care.

Model	Doctor-Patient Relationship	Management decision making style	Doctor patient communication
Non-disclosure	Paternalistic	Physician only	Poor
Full disclosure	Paternalistic	Patient only	Fair
Individualised disclosure	Partnership	Joint	Good

The key steps in effective communication of bad news in clinical consultation are described using the mnemonic SPIKES:

- Setting: yourself, patient, situation
- Patient view/perception: what does the patient know and think of his/her situation

- Invite the patient to know/seek information
- Knowledge giving:
  - Warning shot
  - Small chunks of information
  - Gauge patient's response/understanding
  - Encourage questions, allow enough time
- Emotions managed (Empathise/Validate/Explore)
- Strategy & summary: plan for follow-up, what happens next

### **Important points:**

- Do not withhold information if the patient wants it
- Do not impose information if the patient does not want it
- Gauge and respond to the patient's reaction to the news

## **Module 1c: Ethical issues in palliative care**

### **What is ethics?**

1. Ethics is concerned with moral principles, values and standards of conduct. Can be considered as study of morality.
2. Morality is the value dimension of human decision making and behaviour. It can vary in different communities and cultures.
3. Medical ethics is primarily a field of applied ethics, the study of moral values and judgments as they apply to medicine. It is intended to provide guidelines and codes for health care workers in carrying out their duty, responsibility and conduct.
4. Ethics can be different from legality. For example, infidelity is considered unethical but not illegal in many jurisdictions.
5. Physicians and nurses encounter difficulties in their practice of palliative care. They do need good understanding of ethical principles and precedents.



## **Principles of ethics:**

1. Four principles of Medical ethics
  - a. Autonomy - Patient has the right to make decisions about their medical care including to accept or refuse treatment
  - b. Beneficence –Health Care professional should act in the best interest of the patient
  - c. Non-maleficence - Do no harm
  - d. Justice - Health resources should be distributed equitably and fairly with a societal perspective. People are not discriminated because of race, gender, ethnicity, social or financial status etc.
2. Added to the above four, are two more aspects which form the cornerstones of medical practice:
  - a. Dignity - Patient has the right to dignity
  - b. Truthfulness and honesty –Health care professional should be truthful and honest to the patient
3. Decision making may not always be easy even with this framework in place
4. Ethical conflicts: Disagreements about the right decisions
5. Ethical dilemmas: Situations arising when equally compelling ethical reasons both for and against a particular course of action are recognized and a decision must be made

## **Withholding and withdrawal of treatment:**

1. Futility: Advisability of offering medically futile treatment options to the patient ( eg; Blood transfusion in a terminally ill patient)
  - Physicians are not ethically obligated to deliver care that in their best professional judgment will not have a reasonable chance of benefitting their patients.
2. Withdrawing treatment: Decision to remove an active intervention that is already being provided to the patient.
3. Withholding treatment: Decision not to provide an active intervention.

#### 4. Patient lacking the capacity to make decisions

- Follow advance directives. Advance directives are written documents of patients' views on the extent of medical care they might wish to have in case they happen to be in a situation lacking the capacity to make a decision.
- Find out patient's choices and follow them
- Act in patient's best interests
- We attempt to extend autonomy by allowing others to make medical decisions on their behalf.
- Rather than relying on presumed consent, we should seek a surrogate decision maker. (Ideally one who knows patient's values. But if a surrogate is appointed legally, that person will be the key decision maker)

## Module 1d: Spirituality in palliative care

### What is the problem of Health Care Professionals (HCP) when dealing with spirituality issues ?

Health care professionals are very uncomfortable because they believe they have very little to offer. Regarding death, patients and family often wants to know what to expect . There is often disparity between the religious practices of patients and HCPs religions which creates confusion in HCPs who should have good knowledge regarding local religious and spiritual issues.

### What does the patient / family need?

What they need is relief from symptoms and help with activities of daily living. They need someone to guide in matters related to treatment. They need the compassionate presence of near and dear, someone to talk to and someone who can offer emotional support. Most importantly they need relief from suffering. Suffering is a very personal matter extending beyond the physical to include the mind and spirit.

Spirituality is the spiritual part of our nature that sets us apart from other creatures. It is my being, my inner person. It is who I am, Unique & Alive. It is expressed through my body, my thinking, my feelings, my judgments, & my creativity. It motivates me to choose meaningful relationships & pursuits. Word spirituality is derived from a Latin word *Spiritualitas* meaning breath. Spirituality may be defined as an awareness of the Whole, of which one is a part, which helps one to transcend the tangible to reach new meaning and purpose.

There are 2 aspects of spirituality. The philosophic aspect includes the search for **meaning, purpose and truth** in life and the beliefs and values by which an individual lives. The emotional aspect involves feelings of **hope, love**, connection, inner peace, **comfort and support**.

### How do people find spirituality ?

Many people find spirituality through religion or through a personal relationship with the divine. However, others may find it through a connection to nature, through music and the arts, through a set of values and principles or through a quest for scientific truth.

### What is religion?

Derived from the Latin Religare : to bind together. A religion is a shared framework of theistic beliefs and rituals which give expression to spiritual concerns

### Spirituality Vs Religion

Spirituality gives meaning & purpose to life. Spiritual issues often surface during end of life. Not all are religious but all are spiritual.

Spirituality in our daily life involves learning to forgive, practising gratitude, demonstrating appreciation, giving and receiving and cultivating compassion

<b>Religion</b>	<b>Spirituality</b>
Not just one, there are many.	Only one
For those who need someone to guide them and tell them what to do .	For those who pay attention to their inner voice .
Set of dogmatic rule	Invites us to reason about everything ,to question everything.
Threatens and frightens	Gives inner peace
Speaks of sin and guilt	Says, “ Learn from an error”
Represses all that is false	Brings you closer to your truth
Speaks of a God , not God	Is everything and therefore in God
Does not tolerate any questions	Questions everything
Deals with performing rituals	Deals with inner self
Fills us with dreams of glory in paradise	Makes us live the glory and paradise on earth
Promises life after death	Helps us find God in our interior during the current life before death

## **Meaning and purpose in life**

The search for meaning is one of the primary motivators that keeps us going. When a person comes to a situation where his or her life makes no sense, and there seems to be no meaning or purpose, depression and indifference set in.

## **Religious and spiritual pain**

Religious Pain: feeling guilty over the violation of moral codes & values of his/her religious tradition

Spiritual pain: those who have concluded, through their own self-judgment, that there is something wrong with them at their core.

Spiritual pain involves loss of meaning, loss of hope, loss of identity, lost roles, lost activity, lost independence, anger at God, sense of betrayal, fear of punishment/God, the constant self questioning “Why is this happening to me?” , need for reconciliation/forgiveness

Spiritual pain and distress is associated with negative coping mechanisms mainly in religious field eg sense of punishment or abandonment by God. This is negatively associated with physical and emotional well being which in turn affects QoL.

Spiritual needs include meaningful philosophy of life (values, and moral sense), a trusting relationship with the outside world , experiencing love and forgiveness and a relatedness to nature and people (friendship). Important are the connections that exist with self, the community, the environment and nature, and the transcendent (e.g., power greater than self, a value system, God, cosmic consciousness).

In India, some of the terminally ill would like to spend their last days in sacred places to get mental / spiritual solace.

## **Spirituality as creative expression**

Creative Expressions point us to new paths, new ways of seeing and solving, and which offers us inspiration from both the inside and the outside. It wakes us up, challenges us, and enriches all of life. Those who dive deeply into creative expression make their whole lives a canvas or a blank page onto which their hearts are poured and our world is made better because of it.

## **Spiritual domain**

The map of psyche by Carl Gustav Jung. There are 2 levels for our consciousness, the surface and the deep. The surface plane is the mundane plane active in our wakeful state. Our ego resides in this plane.. The deeper plane is that part of our consciousness that is active during dreaming and at the height of our creativity.

## Connections between the two planes

Whatever we experience in the mundane plane can be connected to the deeper plane where we can discover new meaning and purpose for it. All religions identify this domain and express it through various names. Christians and Jews call it 'God', Hindu call it 'Self' or 'Brahman', Sufi mystics call it 'The Hidden Essence', The Buddhists call it 'Buddha nature' and the Muslims call it 'Allah'.

### **Spiritual distress**

The inability to connect one's experience to the deeper plane. Hence unable to arrive at a meaning to his experience. When threatened by pain and suffering of the illness, the ego clings more and more to the surface plane there by losing the opportunity to connect the experience to the deeper plane where it can get meaning and there by strength and freedom.

### **Pathogenesis of spiritual pain**

Man is not destroyed by suffering, He is destroyed by suffering without meaning'

### **Principles of spiritual care**

Spirituality is an essential component of each person. It is an ongoing issue – readdress it over time. We should demonstrate respect for patient's values, autonomy, vulnerability. Do not impose! KNOW YOURSELF! One should be Listening to the patient's story, Encouraging the search for meaning, Telling of your concern and acknowledging the pain of loss , Generating hope whenever possible and Owing your limitations.

Practice of compassionate presence includes listening to patient's fears, hopes, pain, and dreams, obtaining a spiritual history/ assessing spiritual pain and attentiveness to all dimensions of the patient and patient's family: body, mind and spirit.

### **Assessment of spiritual pain:**

Assessment of spiritual pain includes suspecting spiritual pain, establishing a conducive atmosphere, expressing interest, asking specific questions, listening for broader meanings, being aware of your own beliefs and biases and exploring meaning and value of life, illness religious life, spiritual life etc.

Unresolved issues causing spiritual pain include old feuds or broken relations, last visits, seeing people for the last time, lifetime project, unfinished business, financial plans, need to forgive or be forgiven, loss of control and dignity, loss of relationships, being a burden, and physical suffering

## **Spiritual coping**

Hope: for cure, for healing, for finishing important goals, for a peaceful death, Sense of control, Acceptance of situation, Strength to deal with situation, Meaning and purpose: in life in midst of suffering

### **Taking a spiritual history:**

Two commonly used assessment tools are FICA ( Faith, Influence, Community and address) and HOPE ( sources of Hope, Organised religion, Personal practices, Effects on medical care and end of life)

#### **FICA:**

Faith : Do you consider yourself religious or spiritual? Do you have a faith?

Importance: Is it important in your life?

Community: Are you part of a faith community?

Address :How can we address these issues in your care

#### **HOPE:**

What are the sources of hope in your life?

Do you consider yourself as part of an organised religion?

Do you have any spiritual practices other than/ outside religion?

How is your spiritual /religious belief system affected by the current medical condition?

### **Recognising signs of spiritual distress**

Physical distress unresponsive to standard therapy, patient acting out or refusing to cooperate, emotional withdrawal, fears of loss of control and increasing dependence, denial

High index of suspicion includes sense of hopelessness, feeling of failure with life, lack of sense of humor, conflict with family members, distrusting /mistrusting family members , uncooperative patient and fears of increasing dependence

### **Addressing of spiritual issues**

Take time, ask about and understand the patient's cultural and religious beliefs and customs. Listen to patient's and family's concerns and address them directly.

## Module 2 : Management of pain

### Definition of pain:

International Association for Study of Pain defines pain as “An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage”. For all practical purposes, based on this definition, pain is what a person says, “it hurts” because pain is a subjective phenomenon.

Pain threshold is the minimum intensity of the painful stimulus at which a person begins to perceive, or sense, a stimulus as being painful. Pain tolerance, is the maximum amount, or level, of pain a person can tolerate or bear.

### Acute and chronic pain:

Depending on the duration, it is customary to classify pain as acute and chronic. Acute pain is a pain of less than 3 months duration (some text books set the limit at 6 months) and chronic pain is pain lasting for more than 3 months. There also is an evolving argument that the division of pain into acute and chronic is artificial

- Acute pain is associated with subjective and objective physical signs like hyper activity of autonomic nervous system (increased pulse rate, increased respiratory rate, increased blood pressure, increased muscle tone, sweating etc) and increased basal metabolic rate.
- Whereas in Chronic pain, the autonomic nervous system adapts to the situation and as a result, none of the physical signs associated with acute pain are there. Instead, we will observe changes in personality, lifestyle and functional ability of the patient.

**Break Through Pain (BTP):** Even in patients in whom pain is fairly well controlled for most hours of the day, transient flares of pain can happen. This phenomenon is known as breakthrough pain (BTP)

### Assessment of pain:

Assessment and documentation of pain is important for evaluating the efficacy of therapy, for better understanding of the pain, for encouraging and supporting the patient and for future referencing.

Comprehensive pain assessment will allow the health care professional (HCP) to determine the causes related to psychosocial factors, quality of pain, quality of life and functional status. Such an assessment should include the location of pain, intensity, characteristics, mechanisms, expressions, functions, assessment of the psychosocial factors and the current analgesic treatment if any and response to the same.

Inadequate pain assessment is an important contributing factor for the under treatment of pain.

Assessment of pain is complex because pain is always subjective. The patient's self-report of pain is the single most reliable indicator of pain. The basic principle in assessment of pain is that the clinician must accept the patient's self-report of pain. It is a good practice to use pain diagrams to document the pain at each visit.

### **Pain scales for measurement of intensity of pain:**

Two types of Pain Scales are available.

- I. Unidimensional
  - II. Multidimensional
- Unidimensional scales assess the overall intensity of pain. These take little time to administer and hence are suitable for busy clinical settings.

Any one of the following scales can be used.

- Numeric Rating Scale (NRS)
- Verbal Rating Scale (VRS)
- Visual Analog Scale (VAS)
- Verbal Descriptor scales
- Faces Pain Rating Scale (Observation scale for kids)

**Numerical self-rating scales** (0-10) can be used also with most children older than 8 years of age

- Steps involved in using any of these scales are:
  - I. Explain the scale (what it is for and how it is used) to the patient.
  - II. Ask him/ her to rate the intensity of the pain at the time of assessment.
  - III. Document the intensity mentioned by the patient
- Multidimensional scales explore all dimensions of pain. Since they take time to administer, multidimensional pain scales are not suitable for use in busy outpatient settings.

### **Management of pain:**

Cancer pain can be managed well through a systematic approach. For example, adequate pain relief can be achieved in 70 to 90 percent of patients if proper treatment guidelines for cancer pain are followed.

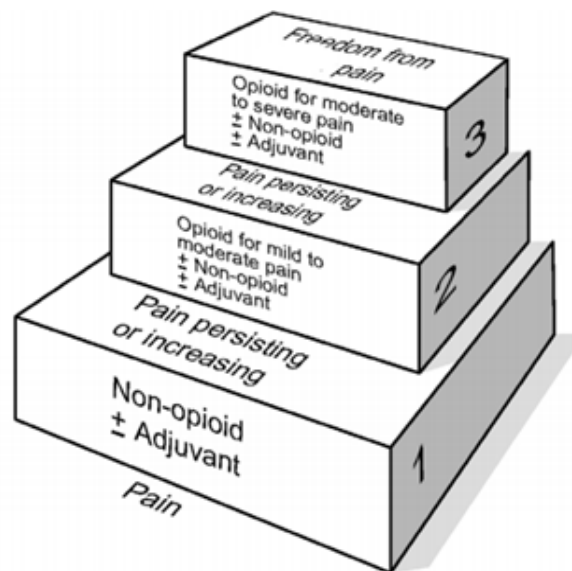


Chronic pain including cancer pain is generally under treated. The reasons for this under treatment are many. Stated reasons include, clinician not having adequate knowledge and skills, patients underreporting pain, barriers to analgesic therapy including existing rules/ regulations and financial concerns.

### WHO analgesic ladder

WHO analgesic ladder is a simple protocol for treating chronic pain. The basic principles of the analgesic ladder are used in pain management, whether patient is on curative or palliative line of treatment. If the patient reports pain, the starting point can be a pharmacotherapeutic strategy based on a stepwise approach according to the severity of pain. The basic principles of using this simple protocol include

- Medications to be given by mouth as much as possible
- Maintaining a steady blood level of analgesics by a 'by the clock' approach and
- Following a stepwise approach



The first step of the ladder consists of non-opioid analgesics, such as paracetamol and the non-steroidal anti-inflammatory drugs (NSAIDs). These act to reduce inflammation and provide pain relief, reducing the production of inflammatory chemicals by inhibition of the cyclooxygenase enzymes. The analgesics in Step I may be combined with an adjuvant drug that provides additional analgesia (ie, a so-called “adjuvant analgesic”, such as an analgesic antidepressant drug for neuropathic pain), treats a side effect, or manages a coexisting symptom. Gastric ulcers and their complications occur in 2–4 % of patients on high doses of NSAIDs which can be prevented if the drug is administered alongside

a proton-pump inhibitor to protect the stomach lining from acid secretion. The dose of acetaminophen (Paracetamol) should not exceed 4 to 6 grams per day to prevent liver damage.

The adjuvant medications referred to by the WHO analgesic ladder are additional drugs that can be added at any step of the ladder. These are not the same as 'adjuvant analgesics', which are drugs with indications other than pain that may be analgesic in certain conditions.

Patients with moderate to severe pain, and those with chronic pain that is less intense but does not respond adequately to a trial of an NSAID alone, should be treated with an opioid. In conditions where prostaglandins play a significant role, such as renal colic, the NSAIDs can be as efficacious as opioids but with a lower incidence of side-effects

Opioids are widely used for treatment of pain in patients with cancer because of their safety, multiple routes of administration, ease of titration, reliability, and effectiveness for all types of pain. Opioids are agonists at mu, kappa and delta receptors, which are located at many sites within the nervous system. Opioids may be pure agonists like morphine, fentanyl, or partial agonists such as buprenorphine.

Morphine is the prototype opioid drug for moderate to severe cancer pain on the third step of the WHO analgesic ladder (WHO ladder ref)]. In the original WHO guidelines, this preference for morphine was not based upon any existing comparative data. Morphine has a short half-life, but it is available in multiple formulations, including immediate-release tablets, sustained release tablets, solution for intravenous (IV) and subcutaneous (SC) use. Sustained -release drugs provide continuous analgesia with once or twice daily dosing. The short half-life formulations are preferred by some patients and may be useful for breakthrough pain when co administered with a long-acting formulation. Regardless of the formulation, morphine is primarily metabolized in the liver and its metabolites are renally excreted. Two active metabolites have been extensively studied, morphine-3-glucuronide (M3G) and morphine-6-glucuronide (M6G). M6G contributes to analgesic activity and M3G may be the cause of some of the side effects that occur during morphine therapy.

There is very large interindividual variation in the response to the different mu agonist drugs and no way to predict whether a patient will have a more favourable balance between analgesia and side effects when given morphine or one of the other drugs.

Fentanyl is 100 times more potent than morphine. As fentanyl is 500 times more lipophilic than morphine, it can be administered by the sublingual, buccal, nasal and transdermal

routes. Methadone is also a highly lipophilic molecule that is suitable for a variety of administration routes. Approved for oral and intramuscular use, it also is used rectally, intravenously, subcutaneously, epidurally, and intrathecally. Oral methadone has a bioavailability close to 80 percent compared with 26 percent for morphine.

The analgesic ladder promotes the concept that one group of opioids should be conventionally used to treat pain of moderate intensity (step 2 of the ladder) and the other group of opioids should be conventionally selected for severe pain (step 3 of the ladder). Step 2 drugs were previously designated with the misnomer “weak” opioids (eg; codeine) step 3 drugs were designated “strong” opioids (morphine as the prototype). On both steps 2 and 3, the approach indicates the potential for benefit with combination therapy that includes an NSAID or other drugs to enhance analgesia or treat side effects.

Frequency of administration of opioid drugs should be at intervals that prevent the recurrence of pain and minimize the number of daily doses. The appropriate dosing interval is determined by the half-life of the opioid used. The analgesic effects of short-acting oral opioids such as morphine, begin within half hour after their administration and should last for four hours. If pain returns sooner, the dose should be increased until the pain continues to be relieved without toxicity during the four-hour dosing interval. Patients with severe, unrelieved chronic pain should have their total daily dose of morphine increased by 50 to 100 percent every 24 hours and those with moderate unrelieved pain can be treated with daily increases of 25 to 50 percent.

Opioid drugs are known for their side effects. Routine inquiry about sedation, constipation, nausea, vomiting, and pruritus should be made to patients on opioids. Constipation is the most common adverse effect of chronic opioid therapy. Laxative medications should be prescribed prophylactically.

Opioids may produce nausea and vomiting through both central and peripheral mechanisms. (stimulation of the medullary chemoreceptor trigger zone, increasing vestibular sensitivity, and effects on the gastrointestinal tract - increased gastric antral tone, diminished motility and delayed gastric emptying. The likelihood of these effects is greatest at the start of opioid therapy. Haloperidol ( 1.5 mg bed time or Metoclopramide 30-40 mg/day can control opioid induced nausea and vomiting.). Since vomiting gets settled within 48 to 72 hours, antiemetics can be discontinued after 2 to 3 days .

Depression of the CNS due to excessive opioid dosing can be readily reversed by the iv administration of the opioid antagonist Naloxone . The duration of action of the antagonist is around 20 minutes so that repeated dosing may well be required.

WHO analgesic ladder approach is important but has its limitations. Although it is still relevant in providing a framework for the stepwise and systematic approach to

managing pain and describing an appropriate role for opioid therapy, many details are not evidence-based. For example, the distinction between weak and strong opioids is pharmacologically outmoded and should not be used to justify the selection of one or another drug.

Evidence-based clinical guidelines now exist for managing cancer pain, and competency in cancer pain management requires a more detailed understanding of the principles of appropriate drug selection, dosing, and other processes of care than were originally built into the analgesic ladder strategy.

## **Neuropathic pain:**

### **Definition:**

The International Association for the Study of Pain defines neuropathic pain as ‘pain initiated or caused by a primary lesion or dysfunction of the nervous system’. This definition was later revised by the IASP Neuropathic Pain Special Interest Group (NeuPSIG) 2008as “pain arising as a direct consequence of a lesion or disease affecting the somatosensory system”

### **Pathophysiology**

Various types of nerve injuries can result in neuropathic pain. Common causes are infections, trauma including surgeries, neurotoxins, metabolic abnormalities, chemotherapy, radiation, nerve compression and tumour infiltration

Neuropathic pain is associated with both peripheral and central sensitization of the nervous system and increase in the sensitivity and excitability of neurons

### **Clinical features:**

Nerve dysfunction caused by blockade of nerve conduction can result in numbness, weakness and loss of deep tendon reflexes in the affected nerve area. Neuropathic pain also causes symptoms of spontaneous and stimulus-evoked pain. Spontaneous pain (continuous or intermittent) is usually described as burning, shooting or shock-like. Stimulus evoked pain includes allodynia (pain evoked by a nonpainful stimulus) and hyperalgesia (exaggerated pain evoked by a painful stimulus). These sensory abnormalities may sometimes extend beyond nerve distributions.

### **Diagnosis**

Many neurologists consider neuropathic pain as a syndrome (combination of specific symptoms and signs with multiple potential underlying aetiologies) and not a single disease..

The following steps have been suggested as the method of assessing the syndrome.

Step I: Anything in the history to indicate whether the character and distribution of the pain is in accord with neuropathic criteria, and whether a relevant lesion or disease in the nervous system is probably responsible for the pain.

Step II: The clinical examination to identify the sensory signs of neuropathic pain

Step III: Diagnostic tests to either document the presence of a specific underlying neurological disease or confirm a sensory lesion within the pain distribution.

Based on this stepwise assessment, patients can be categorized into

- Possible neuropathic pain (positive for step I),
- Probable neuropathic pain (positive for Step I and II)
- Definite neuropathic pain (positive for Step I, II and III)

Various screening tools for neuropathic pain are available. They can be helpful in identifying potential patients with neuropathic pain, but they cannot replace careful clinical judgment as they fail to identify 10–20% of patients with clinician diagnosed neuropathic pain.

### **Treatment**

Majority of patients with neuropathic pain will require combination therapy with more than one drug. It will be a good policy to include opioid drugs in the prescription. Opioids have been found to give partial relief if continued for more than 24 hours.

### **Antidepressants:**

Antidepressants are the mainstay in the treatment of neuropathic pain. Tricyclic antidepressants are the most effective in this group. Analgesic actions are separate from their antidepressant effects, since analgesic effects occur earlier and at lower doses than for antidepressant effects. Analgesic actions of antidepressant drugs are attributed to their effect on blockade of reuptake of noradrenaline and serotonin at the synapses, thereby enhancing descending inhibition of pain.

NMDA-receptor antagonism and sodium-channel blockade have also been postulated to be contributing to analgesia. Selective serotonin reuptake inhibitors ( Citalopram) and mixed serotonin–noradrenaline reuptake inhibitors (venlafaxine and duloxetine), are not as effective as tricyclic antidepressants.

Tricyclic antidepressants may be started at 25 mg/ day, single dose at bed time (10 mg/day in elderly/ frail patients) and slowly titrated up to an effective analgesic dose (maximum 75 mg/day). The dose can be increased every 3rd day, but it will be better, from the side effect point of view to do the titration over a period of six to eight weeks.

Tricyclic antidepressants have a very poor side effect profile which limits its use, particularly at higher doses. Major problems include cardiac conduction block, orthostatic hypotension, sedation, confusion, urinary retention, dry mouth, constipation and weight gain. Anticholinergic adverse effects can be reduced by starting with low doses, slow titration to higher dose, as well as by using a secondary amine tricyclic antidepressants (Nortriptyline /Desipramine instead of Amitriptyline/ Imipramine).

### **Antiepileptics:**

Anti-epileptics can be used in the treatment of neuropathic pain as the first line drugs or in addition to the anti-depressants. Antiepileptic medications have been used for pain management since the 1960s. Gabapentin, Pregabalin, Carbamazepine and Sodium Valproate are commonly used drugs. Gabapentin and Pregabalin are more effective than the other two. However, Carbamazepine, is still considered first-line therapy for trigeminal neuralgia.

Gabapentin, is a-2-delta subunit voltage-gated calcium channel antagonist proven to be effective in ameliorating neuropathic pain. Pregabalin is a gabapentin analogue with a similar mechanism, but with a higher calcium-channel affinity and better bioavailability. Dose of Gabapentin is 300–900 mg/day in divided doses every 8 hour. The usual practice is to increase the dose weekly by 300 mg/day. It may take 1200–2400 mg/day for optimum results. Upper limit is 3600 mg/day.

Pregabalin is administered as 50–150 mg/day, in divided doses every 8–12 hour. Dose is increased weekly by 50–150 mg/day. Optimum results are with doses 300–600 mg/day. Upper limit is 600 mg/day.

Pregabalin provides analgesia more quickly than gabapentin, because the lower initial dose of 150 mg/day itself is often efficacious and also a shorter time is required to titrate to a full dose.

**NMDA antagonist:** Because of the important role that N-Methyl D Aspartate (NMDA) play in central sensitization, NMDA antagonists like the intravenous anaesthetic agent Ketamine can be used in the management of neuropathic pain. Ketamine can be given orally, sub lingually, sub cutaneously or intravenously. Ease of administration and lesser possibility of side effects make oral and sublingual administration preferable to the other routes. The Oral / Sublingual dose is 0.5mg/kg tid to qid. Intravenous administration is 0.25 – 0.5 / kg bolus and subcutaneous as 0.1-0.15mg/kg/hr (100–500mg/day) infusion. Towards higher doses, it can cause delirium, dysphoria, hallucinations and nightmares.

Topical agents like lidocaine( 5% lidocaine patch/ 5% Lidocaine gel) or Capsaicin cream (0.025 or 0.075 %) can be useful as supplements in patients with well localized neuropathic pain.

## Module 3 : Management of symptoms other than pain

### 3 a. Diagnosis and management of gastrointestinal symptoms in advanced diseases

#### Nausea and Vomiting:

Vomiting: Forceful oral expulsion of gastric contents associated with contraction of the abdominal and chest wall musculature

Nausea: The unpleasant sensation of the imminent need to vomit, usually referred to the throat or epigastrium; a sensation that may or may not ultimately lead to the act of vomiting

Regurgitation: The act by which food is brought back into the mouth without the abdominal and diaphragmatic muscular activity that characterizes vomiting

Retching: Spasmodic respiratory movements against a closed glottis with contractions of the abdominal musculature without expulsion of any gastric contents

Pathophysiology of Nausea and vomiting including receptors/ mediators

1. Nausea and vomiting in advanced diseases can be due to different causes. The choice of anti-emetic depends on the cause of nausea and vomiting. Cause can be chemical, gastrointestinal, cranial or other causes
  - a. **Chemical causes** (Drugs including opioids, digoxin, anticonvulsants, antibiotics, cytotoxic chemotherapy, toxins like food poisoning, ischemic bowel, gut obstruction or metabolic organ failure, hypercalcemia, ketoacidosis, uremia and hyponatremia are the common causes)
  - b. **Gastrointestinal causes** (Gastric stasis due to anticholinergic drugs/ ascites/ hepatomegaly/ gastritis, stretch/distortion of GIT due to constipation, intestinal obstruction / mesenteric metastases, serosal stretch/ irritation (liver metastases, ureteric obstruction)
  - c. **Cranial causes** (Cerebral oedema, Intracranial tumour, Intracranial bleeding, Cerebral infections, skull metastases, Meningeal infiltration)
  - d. **Other causes** (Common examples are movement associated nausea and vomiting, anxiety induced nausea and vomiting, anticipatory emesis)
2. Differential diagnosis of nausea and vomiting based on main cause
3. Suggested drugs with dosage for each cause

**a. Chemical causes**

- i. Haloperidol
- ii. 5HT 3 antagonist ( Ondansetron) with corticosteroid

**b. Gastro intestinal causes**

- i. Prokinetic agents
- ii. Drugs to reduce gastric secretions ( Glycopyrrolate, Atropine)
- iii. Corticosteroids

**c. Cranial causes**

- i. High dose corticosteroids

**d. Others**

- i. Movement associated
  - 1. Cinnarizine
- ii. Anxiety induced /Anticipatory emesis
  - 1. Benzodiazepins

- 4. General non-pharmacological measures to complement drug therapy in nausea and vomiting.

***Additional information:***

Main receptors involved in genesis of Chemotherapy induced Nausea and Vomiting (CINV) are D2, 5-HT and Substance P. Emetogenicity of individual chemotherapeutic agents vary. 5-HT3 receptor antagonists are the mainstay of current antiemetic therapy for CINV.

The pathophysiology of radiotherapy (RT)-induced nausea and vomiting (RINV) is similar to that caused by chemotherapy. Nausea is more frequent in those receiving RT to the lower abdomen or pelvis and to the head and neck area. 5HT3 antagonists remain the mainstay of antiemetics for RINV. Addition of corticosteroids have been found to give better results.

Anticipatory emesis is nausea and vomiting occurring prior to chemotherapy as a conditioned response in patients who have developed significant nausea and vomiting during previous cycles of chemotherapy. Prevention of CINV beginning with the initial



cycles of chemotherapy can help in preventing it to a large extent. For patients who do develop anticipatory emesis, benzodiazepines and / or behavioural therapy have been suggested.

General preventive measures such as minimizing the sights, sounds, and smells associated with nausea will be useful. Avoidance of fatty, spicy, highly salted foods is also suggested.

If the patient is in the terminal stage, empirical treatment for nausea with haloperidol or metoclopramide without searching for a specific aetiology has been suggested.

Olanzapine is an atypical antipsychotic known to block several receptors in the emesis pathway.(D2, AChm, 5HT3, H1) High prevention rates for acute and delayed CINV in patients receiving high and moderate emetic chemotherapies have been found. There are reports regarding its efficacy in patients with refractory vomiting in advanced cancers

### **Inoperable malignant gastrointestinal obstruction:**

1. Nausea and vomiting and constipation in a gastro intestinal or gynaecological malignancy can be due to intestinal obstruction
2. Total obstruction is usually associated with colicky pain
3. Drug of choice for inoperable partial gastro intestinal obstruction are prokinetics
4. Drugs of choice for inoperable total intestinal obstruction are a combination of anti-spasmodics, analgesics and anti-secretory drugs.

### ***Additional information:***

Malignant Bowel Obstruction (MBO) is diagnosed if the patient has clinical evidence of bowel obstruction (history/physical/ radiological examination); bowel obstruction beyond the ligament of Treitz (duodeno-jejunal junction), in the setting of a diagnosis of intra-abdominal cancer with incurable disease, or a diagnosis of non-intra-abdominal primary cancer with clear intraperitoneal disease. Clinical presentation is with nausea and vomiting, constipation, abdominal distention, and pain. Confirmation can be by ultra sonogram, X ray in erect position, or preferably CT scan.

If the obstruction is at the gastric or proximal small bowel level, the vomitus will be in large volume, bilious, watery, with no foul smell. Short intermittent peri umbilical pain is an early symptom. Patient will be anorexic. Abdominal distention is not always present.

Obstruction at the distal small bowel or large bowel presents with frequent small volume foul smelling vomitus. Deep visceral colicky pain is a late symptom. Patient may not be anorexic. Abdominal distention is always present.

Surgery is the management option of choice in bowel obstruction. But decision to operate need to be taken based on many patient factors like advanced age, nutritional status, performance status, concurrent illness and co-morbidities, previous and future anticancer treatment. Multiple levels of obstruction preclude surgery. Patients with persistent ascites are also at risk for a poor outcome.

Parenteral nutrition is advised as a short-term option for selected malnourished patients with malignant bowel obstruction who are undergoing surgery to enable subsequent chemotherapy and have a postoperative survival that is likely to be more than three months.

Recent reports show good results in the relief of obstruction and reduction of symptoms with the endoscopic insertion of a self-expanding metal stent (SEMS) if available, or gastric venting via a percutaneously placed gastrostomy (drainage PEG) in patients with poor short-term prognosis.

According to the Working Group of the European Association for Palliative Care Clinical Practice Recommendations for the management of inoperable MBO, the aim of pharmacological management in inoperable MBO should be to relieve continuous abdominal pain and intestinal colic, to reduce vomiting to an acceptable level for the patient (e.g. 1-2 times in 24 hours) without the use of the NGT, to relieve nausea and to achieve hospital discharge to allow for care at home. In addition to symptom relief, medical intervention also aims at enabling the recovery of the bowel transit if possible, by breaking the vicious circle of intraluminal hypertension, oedema of the intestinal wall and local inflammation mediated by prostaglandins and peptides. This can be attempted with corticosteroids like Dexamethasone 6-16 mg/ day

Pain relief can be achieved by giving analgesics, mainly strong opioids, most usually parenterally. The dose of opioids should be titrated against the effect.

Steroids can decrease the inflammation arising in the adjacent bowel, anti secretory agents reduce the intraluminal fluids retention, antiemetics preferably acting on the central nervous system (such as haloperidol) are useful in reducing nausea. Hyoscine Butyl Bromide ( upto 60mg/ day) and Glycopyrrolate (0.2 – 0.4 mg three times a day) are the usual anti-secretory agents in use. Dicyclomine is a weak anti spasmotic which can be used if Hysocine Butyl Bromide is not available. Prokinetic agents like metoclopramide (40-80mg subcutaneously daily) are helpful in partial obstructions (intermittent rather than continuous nausea and vomiting, with some passage of flatus or stool, or ileus) but should be avoided if there is complete mechanical obstruction or colicky pain. A Cochrane meta analysis has found that corticosteroids (Dexamethasone 6-16 mg intravenously/ sub cutaneously) can reduce symptoms of malignant bowel obstruction with a low rate

of adverse effects. Octreotide, the potent somatostatin analogue is a better anti-secretory agent (starting dose of 0.1 mg (100 micrograms) twice daily given subcutaneously and titrated up to 0.3 mg two times a day) than the classic anticholinergic drugs. Resolution of inoperable MBO may occur in 30–40 % of patients. But the drug is very expensive.

Small volumes of oral fluid can be allowed even in patients with unresolved MBO as around 9 litres of fluid pass through the normal gastro intestinal tract every day and it can go upto 11-12 litres in the presence of obstruction. Addition of 100-200 ml by oral route, when requested by the patient will not cause any damage. Sips of fluid helps to keep the mouth moist and suppress the sensation of thirst.

### **Constipation:**

1. Constipation is common in advanced diseases. The use of opioid analgesics is the most common cause of constipation in palliative care, especially in the bedridden, immobile patient. Other possible causes in cancer patients include Hypercalcemia, Intestinal obstruction and Spinal cord compression.
2. Diagnosis of constipation is based on history, physical examination including per rectal examination, X ray abdomen/ Ultra sonogram
3. Laxatives. Onset and duration of action of individual laxatives differ
4. Attention need to be given to
  - a. Other symptoms, especially pain,
  - b. Diet
  - c. Fluid intake
  - d. Mobility
  - e. Privacy for toileting

### ***Additional information:***

Constipation is a common symptom in advanced diseases. Constipation can be defined by bowel movement infrequency, defecatory symptoms, and/or stool consistency. A major contributing factor is opioid-induced constipation, but other factors like decreased intake of fluids, low fibre diet, reduced physical activity, cognitive impairment, lack of privacy etc contribute. In addition to opioids, other common medications as calcium-channel blockers, antidepressants, anticholinergics, and diuretics are also associated with constipation. Currently available formal criteria to define chronic functional constipation (the Rome IV criteria) are not useful in palliative care as they require that symptom onset should occur at least six months before diagnosis, and symptoms should be present during the last three months.

History should include medication history, day and time of last bowel movement, consistency of stool, associated symptoms like rectal urgency, rectal pain, fullness or pressure, abdominal distention, and small stool size. Patients with constipation may also present with abdominal pain, nausea, vomiting. spurious diarrhoea with stool incontinence can be suggestive of longstanding constipation in a frail patient.

Physical examination should include rectal examination which may demonstrate faecal impaction, or an empty rectum suggestive of bowel obstruction. Rectal examination also helps in assessing for masses, anal fissures, haemorrhoids, sphincter tone, prostatic hypertrophy in males, and posterior vaginal masses in females. Radiological imaging of abdomen and pelvis is indicated if bowel obstruction is suspected.

First step in management is to discontinue any medications that cause constipation and can be safely stopped. Rectal-based therapies, such as enemas and suppositories, can be helpful in patients with a prolonged constipation, defecation disorder or symptoms of anorectal obstruction.

Laxatives commonly used in palliative care to treat constipation are softeners and different types of stimulants. Stimulant laxatives, such as Bisacodyl, Senna acting in 6-8 hours, are effective at increasing the frequency of bowel movements by stimulating intestinal motility via the myenteric plexus. Osmotic laxatives have nonabsorbable ion or molecule, which causes an osmotic load into the colonic lumen to stimulate movement. Lactulose is an effective agent belonging to this group. Osmotic laxatives take 1-2 days to act. Polyethylene glycol a quick acting laxative ( 0.5-1 hour) is effective and more palatable due to the lack of taste and ease of titration. It is not routinely used for constipation in many places.

Suppositories/ enema to be used if constipation has been persisting for more than 5 days.

### **Diarrhoea:**

1. Different mechanisms involved in diarrhoea in advanced diseases
2. Revise current medication to rule out drugs as possible cause
  - a. Laxatives
  - b. Mg containing antacids
  - c. Theophylline preparations( Deriphylline)
  - d. CNS drugs
  - e. Antiarrhythmics
  - f. Antibiotics

3. Management consists of
  - a. Oral rehydration solution
  - b. Dietary sugar / aspirin in diarrhoea due to abdominal RT
  - c. Steroids in radiation enteritis
  - d. Nonspecific therapy with Loperamide (4mg stat followed by 2mg after every unformed stools)
  - e. Octreotide for refractory diarrhea ( Remember that it is expensive!)

***Additional information:***

Diarrhoea is the passage of loose stools, typically at least three times in a 24-hour period. Acute diarrhoea is defined as diarrhoea of  $\leq 14$  days in duration, in contrast to persistent ( $>14$  days and  $\leq 30$  days) or chronic ( $>30$  days) diarrhoea. Diarrhoea with visible blood is called Dysentery.

Adequate fluid and electrolyte replacement and maintenance are the key to the management of diarrhoea. Antimicrobials are indicated only in infectious diarrhoea and dysentery. Diarrhoeal illness with minimal to moderate dehydration can be treated with Oral Rehydration Solution. Severe dehydration will require intravenous fluids.

Persisting non-infectious diarrhoea can be managed symptomatically with loperamide an initial dose of 4 mg, followed by 2 mg every four hours or 2 mg after each loose stool. Octreotide is recommended first-line for chemotherapy or radiotherapy-induced diarrhoea when severe (i.e., an increase of  $\geq 7$  stools/24 h over baseline, hospital admission and IV fluids required for  $>24$  h), and second-line for less severe diarrhoea which does not respond to loperamide 16–24 mg/24 h.

### **3 b. Basics of management of respiratory symptoms**

1. Dyspnoea is subjective experience of breathing discomfort due to increased sense of respiratory effort and perception of demand mismatch. Dyspnoea is a common symptom in advanced diseases, particularly in cancer. Psychological factors may precipitate or worsen dyspnoea.
2. Steps in basic management include
  - a. Assessment of dyspnoea
    - i. history
    - ii. rating the intensity

- iii. physical examination
  - iv. selective investigations ( X ray, Ultrasonogram) if appropriate
- b. Correct the correctable (e.g. infections, anaemia)
  - c. Explain the ‘Breathing, Thinking, Functioning’ model
  - d. Referral for management of specific dyspnoea syndrome if any ( eg; malignant pleural effusion, malignant cardiac disease and pericardial effusion, superior venacaval obstruction, pulmonary lymphangitis carcinomatosis)
  - e. Role of oxygen:
    - i. Oxygen need not always be beneficial in breathlessness in advanced disease. Many studies have shown that dyspnea at the end of life is not related to hypoxia.
    - ii. A practical solution can be a therapeutic trial of oxygen. Administer oxygen (4 liter/ minute) for a period of 15 minutes after explaining to the patient that it can be continued if beneficial. It can be discontinued after 15 minutes if the patient does not find it helpful.
  - f. Pharmacological management:
    - i. Opioids are the drug of choice in the symptomatic management of dyspnoea. They act through multiple mechanisms
      1. Morphine is the most commonly used drug.
      2. If the patient is already on morphine for pain, the dose can be increased by 30%–50%.
      3. If the patient is not already on morphine, it is customary to start with 2.5 to 5 mg q4h – q6h.
      4. Morphine can be supplemented by small doses of anxiolytics.
      5. It might be helpful to give a trial of Morphine to see if it is effective
    - ii. Other useful drugs include:
      1. Corticosteroids(dexamethasone4–8mg/day)in superiorvenacaval obstruction, lymphangitis carcinomatosis, airway obstruction (e.g. tracheal tumours), pneumonitis (after radiotherapy).
      2. Bronchodilators have a role if bronchospasm is present

g. Non-pharmacological management:

- i. provide care to the patient in a well-ventilated room
- ii. fan should be switched on or use a hand fan
- iii. loosen the garments worn
- iv. make the patient sit or lie down in his / her most comfortable position.
- v. make arrangements for him to lean comfortably when seated. Give water as and when required
- vi. do not allow people to crowd in the patient's room
- vii. breathing and relaxation techniques can be useful if patients had former training in Breathing techniques before the acute episode of dyspnoea.

## Module 4 : Emergencies in palliative care

### Spinal cord compression

1. Spinal cord compression occurs in up to 5% of cancer patients
  - a. 10% patients with vertebral metastasis develop spinal cord compression
  - b. Features are subtle in early stages
  - c. It will be too late for active intervention by the time classical features develop
2. Malignant spinal cord compression is common in
  - a. Multiple myeloma
  - b. Cancers of Breast, Bronchus, Prostate, Bladder, Kidney
  - c. But can happen in any malignancy
3. Vertebral level of compression is
  - a. 10% in cervical segment
  - b. 70% in thoracic segment
  - c. 20% in lumbo-sacral segment
4. Mechanisms can be any of the four
  - a. Erosion of vertebral body metastasis in to epidural space (85%)
  - b. Vertebral collapse
  - c. Spread through intervertebral foramen
  - d. Interruption of vascular supply
5. Back pain can be an early warning symptom
  - a. But it is nonspecific as low back ache of benign aetiology occurs annually in 5% and over a lifetime in 60–90% of the entire population
6. More relevant will be back ache, ↑ on supine position, Root pain (“bands”) ↑ by strain
7. Other signs
  - a. Stiffness → Weakness



- b. "Difficulty in climbing up stairs"
  - c. Altered sensations in feet, ascending up
  - d. Urinary symptoms and perianal numbness are late signs
8. Clinical examination to localise the lesion (eliciting tenderness over spine)
9. Investigations
  - a. X-Ray (positive findings seen only after > 50% of bone destruction)/ CT Scan/ MRI (investigation of choice)
10. Emergency Management
  - a. Corticosteroids (Dexamethasone >16mg i.v daily as single dose)
  - b. Refer to Radiotherapy after starting steroids
  - c. Adjuvant Chemotherapy sometimes beneficial
  - d. Need for an interdisciplinary approach
11. Indications for Surgery
  - a. Tissue diagnosis required
  - b. Deterioration during Radiotherapy
  - c. Bone destruction with spinal instability
12. Regaining ability to walk after RT
  - a. 70% of patients ambulatory at the time of starting RT
  - b. 30% of paraparetic patients
  - c. 5% of paraplegic patients
13. Poor prognosis - 1/3 may survive for an year
14. Long term management of patients with irreversible compression of spinal cord included
  - a. Mobility & protection of spinal cord
  - b. Skin care, bowel interventions
  - c. Urinary system management
  - d. Psychosocial support

## Superior venacaval obstruction

1. SVC obstruction is caused by tumour in the mediastinum preventing venous drainage from the head, arms and upper trunk.
2. Most commonly seen in patients with lung cancer, lymphoma, large lung metastases,
3. Patients with central intravenous lines are also at risk due to clot formation.
4. Usually occurs over weeks or months
  - a. Gets time for collateral circulation to develop.
5. Occasionally occurs acutely, when it becomes an emergency
6. Signs and symptoms
  - a. Persistent headache and feeling of fullness in the head.
  - b. Oedema of face and arms that is usually bilateral, worse in the morning and may fluctuate over the day.
  - c. Early morning oedema of the eyelids making it hard for the patient to open their eyes is an early sign.
  - d. Dusky colour to the skin of chest wall, arms or face with distended superficial veins.
  - e. Breathlessness, worse on lying flat.
7. Investigations
  - a. Chest X ray may help in identifying the mass
  - b. CT scan of chest may identify the mass
  - c. Venography if planning to insert a stent
8. Management
  - a. Consider admission to hospital
  - b. Start Dexamethasone 12-16 mg single dose/day. Continue until other interventions. Taper and stop later as dictated by the patient's condition.
  - c. Possibility of chemotherapy/radiotherapy/insertion of an SVC stent to be considered
  - d. Opioids to manage headaches and breathlessness

## Hypercalcemia of malignancy

1. Hypercalcemia is defined as serum calcium (corrected) greater than 2.6 mmol/L (greater than 10.3 mg/dl)
  - Corrected calcium (mmol/L) = Measured calcium (mmol/L) + [0.02 x (40 – measured albumin g/L)]
2. Occurs in 10% to 40% of cancer patients.
  - Usually in patients with advanced cancer
  - An indicator of poor prognosis
3. Influx of calcium to the extracellular space from bone resorption exceeds the rate at which it can be excreted by the kidney. Paraneoplastic syndrome, secondary to secretion of PTH like substances, also has a role to play.
4. Common cancers associated with hypercalcemia
  - Multiple myeloma – 40% to 50%
  - Breast – greater than 20% of cases with cancer-related hypercalcemia
  - Lung – 20%, usually squamous cell, sometimes adenocarcinoma, rarely small cell
  - Hypernephroma
  - Squamous cell cancers of the head and neck and esophagus
  - Thyroid
5. Symptoms
  - GIT: Nausea, vomiting, anorexia, constipation
  - Renal: Thirst and polyurea
  - CNS: Malaise, confusion, coma, reduced pain threshold
6. Management
  - Extracellular volume repletion until a good urine output (2 L/day) established
    - 3–4 L 0.9% saline / first 24 hours / 2–3 L / 24 hours thereafter
  - Intravenous Bisphosphonates (Zoledronate 4-8 mg IV )

- Do not give bisphosphonates until the patient is fully re-hydrated and has an adequate urine output
  - Renal failure is the most serious adverse effect
  - Calcitonin can be useful in severe hypercalcemia in patients with compromised renal function
7. Addressing symptoms (eg; Haloperidol for nausea)
  8. Recheck serum calcium, electrolytes, urea, and creatinine on the 3rd day after administering bisphosphonates. Give a second dose if necessary
  9. Repeat Bisphosphonates after 3-4 week

### Major hemorrhage

1. In the event of severe haemorrhage, / risk of a bleed significant, a discussion with patient/ family may be needed to reach an informed decision about possible treatment options.
2. It may not be appropriate for patients at the end of life to be transferred to another site for interventions that may not confer significant survival benefit or add to quality of life.
3. Assessment/ interventions:
  - a. Site(s) of bleeding:
    - i. External bleeding: apply a dressing to reduce bleeding and protect the wound from trauma and infection.
  - b. Size of bleed:
    - i. Pulse, lying and standing BP (a postural blood pressure drop is often the first sign of blood loss)
    - ii. Positive 'shock index' - pulse rate (in beats per minute) is greater than the systolic blood pressure (in mmHg).
  - c. Check for dehydration
  - d. A disproportionately high blood urea may suggest a gastrointestinal bleeding source

4. Fluid resuscitation if appropriate
  - a. Secure IV access
  - b. Maintain blood pressure and vital organ perfusion
5. Look for reversible causes
  - a. Review medications and consider stopping drugs that adversely affect clotting
  - b. In case of bleeding from a number of different sites, consider an underlying coagulopathy and whether this should be corrected
  - c. If infection is thought to precipitate haemorrhage, consider wound swabs and cultures for microbiological identification of pathogens and antimicrobial sensitivities
6. Useful drugs
  - a. Consider use of oral tranexamic acid (1g TDS)
  - b. There is anecdotal evidence for the use of Ethamsylate 500mg qds for bleeding
  - c. There is anecdotal evidence for the use of Dexamethasone 2 mg for bleeding
7. Major catastrophic bleed
  - a. Stay calm, summon assistance
  - b. Ensure that someone is with the patient always
  - c. If possible nurse in recovery position to keep air way clear
  - d. Mask/ disguise bleeding with dark towels/sheets
  - e. Apply pressure to the area if bleeding from external wound with adrenaline soaks if available
  - f. Administer sedatives ( eg; Midazolam 3-5 mg intravenously) . Can be repeated after 10minutes if needed.
8. Regularly review the treatment plan and ensure that planned management is documented and communicated clearly to all staff involved in the patient's treatment.

## Delirium in advanced diseases

1. Delirium is a common problem in advanced diseases. It is a symptom caused by multiple factors in a vulnerable patient
2. Delirium is always sudden and has a fluctuating cause. Diagnostic features include disorientation in time/place/person, fluctuating levels of consciousness/awareness, poor attention and concentration, sleep disruption and hallucinations
3. Common risk factors include advanced age, pre existing dementia, visual/ hearing impairment, history of alcohol abuse
4. Causes are multifactorial
  - a. Drugs (Opiates, Anticholinergics, Steroids, Benzodiazepins)
  - b. Drug withdrawal (Alcohol, Sedatives)
  - c. Dehydration, constipation, retention, uncontrolled pain
  - d. Infection, hypoxia, brain tumours/vascular, liver/kidney dysfunction, electrolyte imbalance
5. Correct the correctible
6. Non-pharmacological supportive measures have a major role in the management of Delirium
  - a. Reassurance, slow, clear instructions, well lit room with place/ date reminders, reduced noise levels, encourage self care
7. Pharmacological management is by low dose haloperidol( 3 mg/ day), Benzodiazepins in Delirium Tremens and delirium in a patient with Parkinsonism. The current advice is to avoid medicines as much as possible to treat delirium.

## Severe pain

1. Rapid titration of intravenous opioids to manage severe pain
  - a. Provides immediate relief of the agonizing pain to most of the patients, with tremendous psychological impact.
  - b. Gives a rough idea of the opioid requirement of the patient.
  - c. It indicates how much the pain is responsive to opioids

2. Intravenous morphine titration - Calicut protocol
  - a. Patients with severe pain
  - b. Quick initial clinical evaluation
  - c. Assess pain
  - d. Rule out bronchospasm
  - e. Secure intravenous access
  - f. Metoclopramide 10 mg intravenously
  - g. Increments of intravenous morphine as 1.5 mg boluses slowly every 10 minutes,
  - h. Assess pain relief and any subjective side effects before each bolus
  - i. Total pain relief or drowsiness as end point
3. Intravenous morphine – French protocol
  - a. Intravenous morphine titrated every 5 minutes by 3-mg increments (2 mg in patients weighing  $\leq 60$  kg)
  - b. Pain assessed every 5 minutes until pain relief, defined as a VAS score of 30 or lower
  - c. 99% of patients had pain relief
  - d. Respiratory depression in 2.6%
4. Oral morphine titration – European Association of Palliative Care
  - a. Oral morphine 5mg every 4 hours in patients not exposed to opioids before
  - b. Rescue doses of the same amount as and when required with a minimum of a one-hour gap between two successive doses.
  - c. Morphine 10 mg every four hours in patients who are already on weak opioids
  - d. Rescue doses of 10 mg as and when required with a minimum of a one-hour gap between two successive doses.
  - e. Reassess after 24 hours to readjust the dose
5. Intravenous fentanyl
  - a. The duration of analgesia after a single bolus dose is only 30 – 60 minutes.
  - b. 1  $\mu\text{g}/\text{kg}$  of intravenous fentanyl, followed by 30  $\mu\text{g}$  every 5 minutes till attain pain relief

6. Low dose ketamine
  - a. Less than 0.6 mg/kg of ketamine for pain control. Can be given sublingual/ oral/ subcutaneous/ IV
7. Intravenous acetamenophen
  - a. Infusion of 1 g every 4–6 hours, with a maximum daily dose of 4 grams.
  - b. Children of 2 years of age and older/ adults weighing less than 50 kg
    - i. 15 mg/kg every 6 hours
  - c. Children under 2 years of age
    - i. 10 mg/kg every 4–6 hours
  - d. Neonates and premature infants
  - e. 7.5 mg/kg every 6 hours

### **More information on emergencies:**

Response to a medical emergency in palliative care setting should be considered more in terms of the patient's clinical context than of the event itself. Decisions should consider the natural history and prognosis of the disease, patient's performance status, patient's and family's wishes, burden and likely outcome of treatment and symptom burden of the condition. Decisions about escalation of care are a difficult aspect when managing palliative care emergencies. Although unnecessary interventions and hospital admission may cause significant distress to patients and carers, missed emergency treatment of potentially reversible conditions may be disastrous. Managing the same palliative care emergency in two different patients may require a very different approach. When intervention is inappropriate, early discussion with staff, patient and family of what may lie ahead can avoid the stress of unexpected developments. Such discussions need to be approached sensitively to minimize anxiety that the event may happen.

### **Impending spinal cord compression:**

Compression of the spinal cord or Cauda Equina common in cancers that metastasize to bone (breast, lung, kidney, prostate and thyroid) and is usually caused by expansion of vertebral body metastases into the spinal canal. Early diagnosis and appropriate management are vital in minimizing long-term disability: 50% of patients with Metastatic Spinal Cord Compression (MSCC) are unable to walk by the time of diagnosis, with 67% regaining no function after 1 month. Around 10% of compressions occur at the cervical level of the spine, 70% thoracic and 20% lumbosacral, but there may sometimes be more



than one site/level of compression. Multiple myeloma, lung cancer and breast cancer are the most common cancers causing MSCC. Sarcomas, neuroblastomas, germ cell neoplasms and Hodgkin Lymphoma are the most frequent causes in children.

The initial symptom of spinal cord compression is usually localized back pain caused by the underlying metastasis. High level of clinical suspicion is needed for patients with symptoms suggesting spinal metastases. (pain in the middle (thoracic) or upper (cervical) spine, progressive lower (lumbar) spinal pain, severe unremitting lower spinal pain, spinal pain aggravated by straining (coughing, sneezing), localized spinal tenderness, nocturnal spinal pain preventing sleep). Pain is often worse with recumbency and at night, possibly related to distension of the epidural venous plexus when laying down or to diurnal variation in levels of endogenous corticosteroids. Weak legs (eg; difficulty in climbing stairs) or vague sensory symptoms in the lower limbs may also be an early symptom. Progressive compression can later cause progressive numbness, objective sensory loss, weakness and finally loss of bowel and bladder sensation. The progression of motor findings prior to diagnosis typically consists of increasing weakness followed sequentially by loss of gait function and paralysis.

It is important to diagnose the condition early as the outcome in patients with spinal cord compression is very much dependent on the speed of diagnosis and treatment. Patients who are ambulant when treated usually remain so; those who are not, do not usually recover.

Physical examination can pick up a well-defined sensory level weakness, altered muscle tone and extensor or absent plantar responses. The signs can be subtle and their absence does not exclude significant spinal cord compression. MRI of the Spine is the investigation of choice.

The immediate management of a suspected cord compression is:

- Nursing the patient flat until a definitive diagnosis has been made
- Injection Dexamethasone 16 mg intravenously which should be given as soon as the diagnosis is suspected
- insertion of a catheter if the patient has urinary retention.

External Beam Radiotherapy (EBRT) is the main option in management. EBRT is effective for palliation of pain and local tumor control. Surgery is considered if there is spinal instability or disease progression despite radiotherapy. Prognostic factors associated with shortened survival after RT include radioresistant tumour, presence of visceral metastases or other bone metastases, non-ambulatory status at treatment, an interval of less than 15 months from the original diagnosis to Spinal Cord Compression and an interval more than 14 days from the onset of motor symptoms to the initiation of RT.

Chemotherapy is not used to treat MSCC as most tumours causing Spinal Cord Compression are not chemo sensitive. Chemotherapy can be a treatment option in chemo sensitive malignancies like Hodgkin lymphoma, non-Hodgkin lymphoma, neuroblastoma, germ cell neoplasms, and breast cancer.

Patients in whom treatment is unsuccessful or inappropriate are likely to develop progressive disability including paraplegia. They will probably require long-term nursing care. Bowel and bladder problems may require long-term catheterization and regular stimulant laxatives (e.g. bisacodyl suppositories).

Malignant Spinal Cord Compression is a condition associated with poor prognosis. The median survival for patients ambulatory prior to RT is eight to ten months compared to two to four months for those who are non-ambulatory. For those who remain non-ambulatory after RT, the median survival is only one month.

### **Superior vena caval obstruction**

Superior vena caval obstruction (SVCO) is caused by extrinsic compression of the superior vena cava (SVC) by the tumour, venous thrombosis being a less common cause. Common tumours causing SVCO are lung cancer, mediastinal lymphoma and metastatic breast cancer. The incidence of SVC syndrome due to thrombosis on the rise, largely because of increased use of intravascular devices, such as catheters and pacemakers.

Examination will show oedema and/or venous distension of the upper body and cyanosis, especially when SVCO develops rapidly before collateral vessels can be formed. The diagnosis is clinical, but chest radiography and computed tomography (CT) can show the extent of the disease.

In an emergency situation, where breathlessness is an acute concern, sit the patient upright. Using opioids (with or without benzodiazepines) titrated to settle breathlessness and anxiety.

Dexamethasone 16 mg intravenously can shrink the extrinsic cause of the SVCO. Dexamethasone can be given for 5 days and then stop if not effective or gradually tailing off if effective or as other treatments take effect. Low-molecular-weight heparin (LMWH) can be given if thrombus is a causative factor. Glucocorticoids can be effective in reversing symptomatic SVC syndrome caused by steroid-responsive malignancies, such as lymphoma or thymoma. Diuretics can also be helpful. If facilities are available, symptomatic relief can be achieved by inserting a stent into the SVC under radiological control. Radiotherapy, can be considered if a tumour is causing compression, but it will take time to act.

The average life expectancy among patients who present with malignancy-associated SVC syndrome is approximately six months, though there is wide variability depending on the underlying malignancy.

## **Hypercalcemia**

Hypercalcaemia is the presence of abnormally high levels of calcium in the blood. The normal range for calcium is between 2.10 and 2.55 mmol/L. This is the most common metabolic emergency in oncology. Up to 40% of patients with myeloma or metastatic breast cancer may be affected at some time in the course of their disease. Overall, about 10% of patients with malignancy develop hypercalcaemia.

Active treatment depends both on the absolute level of hypercalcemia and the patient's symptoms. Asymptomatic patient with a corrected calcium less than 3 mmol/L may need only monitoring. Symptomatic hypercalcaemia and/or corrected calcium greater than 3 mmol/L will need urgent intervention through rehydration with intravenous fluids and bisphosphonate infusion. Following treatment, it is 2–3 days before calcium levels decline to normal. Relapse often occurs after 3–4 weeks and maintenance using regular monthly infusions of Bisphosphonates will be needed.

The steps involved are:

1. Rehydration – give at least 2 litres of normal saline. Administration of isotonic saline at an initial rate of 200 to 300 mL/hour that is then adjusted to maintain the urine output at 100 to 150 mL/hour is the usual norm if the patient is not oedematous.
2. Start intravenous bisphosphonate – zoledronic acid, 4 mg over 15 minutes if renal function is adequate.
3. Continue rehydration for 72 hours or until biochemical markers of dehydration return to normal
4. Ensure adequate oral fluid intake
5. Check serum calcium after 3–5 days and again after 3 weeks
6. Maintenance with monthly zoledronic acid, 4 mg over 15 minutes

Denosumab, can be an option in patients with renal impairments as unlike bisphosphonates, this drug is not cleared by the kidneys.

Salmon calcitonin (4 international units/kg) administered intramuscularly or subcutaneously every 12 hours with saline hydration is an option for emergency management of severe Hypercalcemia. Serum Calcium comes down rapidly, but efficacy of calcitonin is limited to the first 48 hours, even with repeated doses.

## Major hemorrhage

6 to 14% of patients with advanced cancer can present with bleeding and it is considered to be the immediate cause of death in around 6% of cases.

Haemorrhage is often thought of as 'unpredictable', but a major bleed is more likely in patients with head and neck tumours in close proximity to the major vessels, patients with pancreatic tumours in close proximity to the coeliac plexus, lung cancer patients with history of frequent small-volume haemoptysis and patients with fungating tumours. Carcinoma lung invading the aorta, a neck tumour surrounding the carotid artery, or malignant nodes in the axilla or groin eroding a major blood vessel can produce sudden, terminal haemorrhage. Resuscitation is inappropriate in such patients as attempts to ligate major blood vessels will be futile or will lead to limb ischaemia and further distress.

Management strategy includes staying with the patient, giving sedative medication (midazolam 10 mg slowly and repeat given intravenously if possible or otherwise intramuscularly/ subcutaneously but drugs given subcutaneously are poorly absorbed in circulatory shutdown) and supporting the carers. The patient should be sedated using a benzodiazepine. Family and staff may be distressed by the sight of large amounts of blood; the use of red or green towels reduces the visual impact.

## Delirium

Delirium is common in advanced diseases. The incidence varies depending on the stage of illness, with the higher number occurring at end of life. Delirium is observed in approximately one in five general hospital admissions and up to 85% of patients with terminal illness.

Diagnostic features include

1. A disturbance in consciousness with reduced ability to focus, sustain, or shift attention,
2. A change in cognition that is not better accounted for by a preexisting, established, or evolving dementia,
3. The disturbance that develops over a short period (hours to days) and tends to fluctuate during the course of the day
4. The evidence that the disturbance is caused by the direct physiological consequences of a general medical condition.

Additional symptoms include alteration in sleep-wake cycle, short- and long-term memory deficits, delusions, hallucinations, and emotional lability.

Causation is multifactorial in most cases. Precipitating factors were identified in a general medical geriatric population include the use of physical restraints, malnutrition (serum albumin <3.0 g/dL), the addition of more than three medications, the use of bladder catheterization, and iatrogenic events.

A full history and examination should look for evidence of infection, hypoxia, dehydration and major organ failure. Medications should be reviewed to find those that might have precipitated or contributed to the delirium (e.g. opioids, psychoactive medications, sedation, anticholinergics, corticosteroids).

One of the key differential diagnoses is dementia vs. delirium further complicated by the fact that delirium can happen in the setting of pre-existing dementia. Delirium has a sudden onset and fluctuating course, whereas dementia has a slow progressive decline, the history of which can be obtained from family. Both diagnoses will have cognitive impairment, but dementia may have more severe cognitive impairment and more severe impairment in level of consciousness. Delirium superimposed on dementia will also have more severe cognitive impairment. An acute behavioural change is the most consistent with delirium even in the setting of pre-existing dementia.

The appropriateness of investigation in a patient with advanced disease presenting with delirium is guided by the patient's condition, prognosis, practical limitations, invasiveness of the investigations and nature of any possible treatment options in that patient. It may not be relevant to identify problems that would not be treated.

Management of delirium involves determining the aetiology, correcting the correctible ( eg; removal of any medication that might contribute to delirium, management of dehydration and hypercalcaemia) are example and treating the symptoms. The patient's family should be kept fully informed. For some patients, symptomatic and supportive therapies alone can be appropriate. These include fluid and electrolyte management, orientating the patient, employing the help of family and one-to-one nursing in a well-lit room if required. Establishment of an orientation protocol (Provision of clocks, calendars, windows with outside views, and verbally re-orienting patients), cognitively stimulating activities(eg; regular visits from family and friends), nonpharmacologic sleep protocol (Avoiding nursing and medical procedures during sleeping hours, reduction of night-time noise), early mobilization (may not be always possible in the case of palliative care patients), and obtaining vision and hearing aids are all important.

Low-dose haloperidol ( less than 5mg/ day)can be effective in those who need drug therapy. Benzodiazepines are the drugs of choice for withdrawal delirium from alcohol or benzodiazepines or and delirium associated with Parkinsonism. In the palliative care literature, 26% of terminal delirium was not manageable without benzodiazepine-induced sedation. The current advice is to avoid medicines as much as possible to treat delirium.

### **Severe pain**

Optimal management of pain continues to be a challenge, with the prevalence of undertreatment of pain being very high.

Systemic treatment of severe pain as an emergency generally fall into 1 of 3 categories: (1) opioids, (2) nonsteroidal anti-inflammatory drugs and acetaminophen, and (3) combinations of opioids with acetaminophen/ nonsteroidal anti-inflammatory drugs.

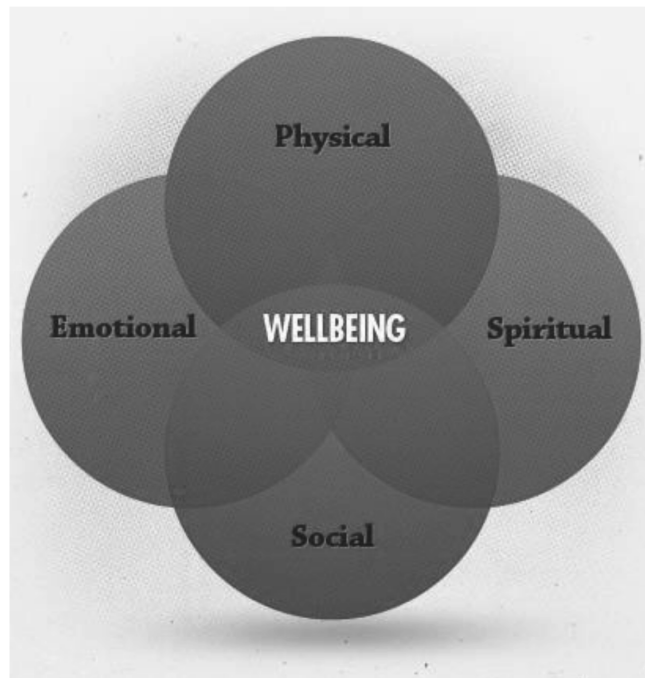
Intravenous morphine (0.1mg/ kg and 0.15mg/kg) has been proved to be effective in controlling severe pain.

The combination of small-dose ketamine (0.2 mg/kg intravenously) and morphine would reduce pain with a lower dose of morphine compared with morphine alone in trauma patients with severe acute pain in emergency settings. Low dose Ketamine (5 -35 mg/dose) on its own can be an effective analgesic.

## Module 5: Palliative care for children, elderly and patients with non-malignant diseases

The differences between adult and paediatric palliative care (PPC)

Children are not just little adults. PPC requires attention to physical, developmental, psychosocial, ethical, spiritual and relational phenomena that are unique to children.



- Prognosis, life expectancy and functional outcome often less clear. Greater emotional burden for family members and clinicians because serious and life-threatening illnesses are not considered normal in children.
- Children undergo continual developmental change: physical, hormonal, cognitive, expressive and emotional.
- Children have changing information needs, recreational and educational needs, and modes of coping with stress. Pharmacokinetics and pharmacodynamics are different in children.

## Pain in children

Pain is the initial symptom of many childhood diseases. Children with terminal illnesses such as cancer experience pain from the cumulative effects of progressive disease, invasive procedures, treatment, and psychological distress. Children, like adults, can suffer neuropathic pain from complex regional pain syndrome, peripheral nerve or spinal cord injury.

### Common myths about pain in children

Myths	Facts
Children do not feel pain	All children feel pain, including infants
Children do not remember pain	All children, even babies, remember previous painful experiences
Children cannot report their pain	There are good tools to help measure pain in all ages of infants and children

## Management of chronic persistent pain in children

### Assessment of pain in children

Optimal pain management begins with accurate and thorough pain assessment. It should be carried out at regular intervals because the disease process and the factors that influence pain may change over time. Regular assessment permits the measurement of the efficacy of different treatment strategies in relieving pain. Pain is measured using one of the available validated pain assessment tools. The pain assessment process involves the child, the parents or caregivers and the health-care providers.

### Pain scales used in pediatric population

Behavioural scale		FLACC Scale
Self- Report		
Physical Measures	Poker Chip, Finger Span	3-6 yrs
	Faces Pain Scale Revised	4-12 yrs
Visual Analogue Scales		≥6 yrs

### In case the scales fail, what is to be done:

If none of the common pain scales are working, try,

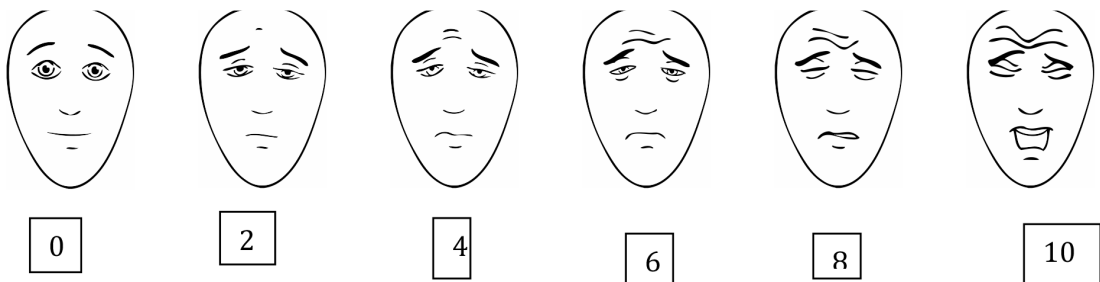
“Do you have a small pain, medium pain or big pain?” Hands/ Fingers can be used to denote the size.



## Physical Measures: Poker Chip, Finger Span



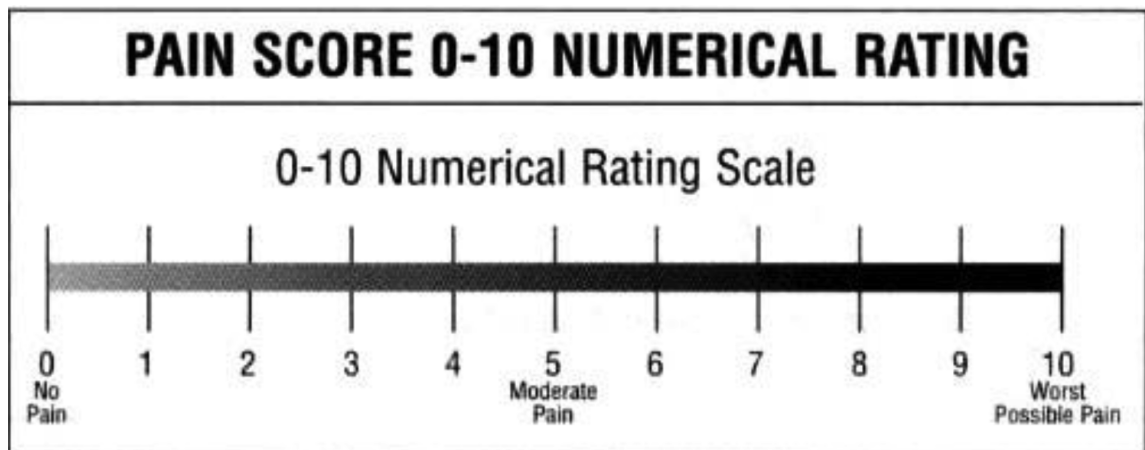
## Faces Pain Scale



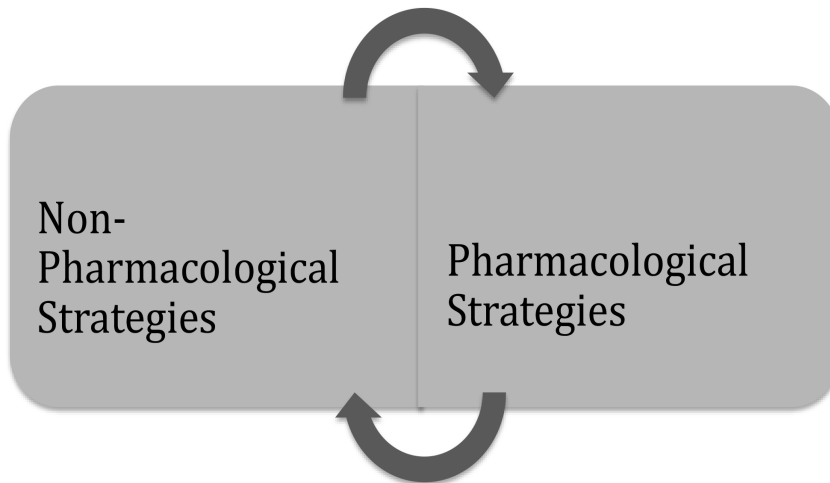
“These faces show how much something can hurt. The first face shows no pain. As you proceed towards right, the faces show more and more pain up to the last face. Point to the face that shows how much you hurt right now.”

Use only for SELF-REPORT: do not match to child’s face

## Numerical Rating Scale



## Management of pain



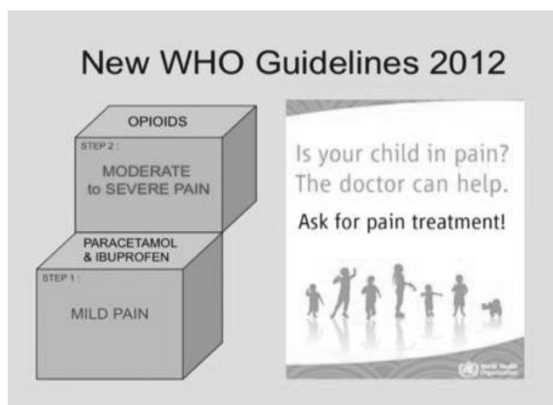
### Pharmacological management of pain

The World Health Organisation (WHO)-Guidelines are found to be effective for analgesia in children with cancerpain. The analgesic ladder provides an excellent framework for the use of analgesics.

*The two-step approach is recommended to be a more effective strategy for the management of persisting pain in children with cancer than the WHO three-step analgesic ladder.*

*Step one analgesics for mild to moderate pain.*

*Step two analgesics for moderate to severe pain.*



Step 1: Mild to moderate pain

- Acetaminophen
- Ibuprofen

Step 2: Moderate to severe pain

- Morphine (Strong Opioid)

Avoid weak Opioids (Tramadol, Codeine)

- Lack of evidence and concerns about safety in children

## Routes of administration

Analgesia should be given to children by the simplest, most effective, and least painful route. Oral analgesia is usually the first choice.

## Analgesic medications

### 1. Non-opioids

#### Paracetamol (Acetaminophen)

**Paracetamol** is generally well tolerated in children and is very useful for mild pain. It is available in a variety of oral preparations and for rectal use (not appropriate for neutropenic patients). It is safe in patients with renal impairment, bleeding disorders and acid-peptic disorders.

#### Non Steroidal Anti-inflammatory Drugs (NSAIDs)

These are powerful anti-inflammatory agents with analgesic and anti-pyretic activity. They may be helpful in alleviating musculoskeletal pain such as that induced by bone metastases and soft tissue inflammation.

#### Adverse reactions

They should be used with caution in children with thrombocytopenia, coagulation disorders, gastrointestinal ulceration or bleeding and significant renal impairment.

#### Selective Cox 2 inhibitors (Coxibs):

Reports of the use of COX-2 selective inhibitors in children are appearing in the literature. COX 2 inhibitors offer certain advantages in that the risk of gastrointestinal bleeding is reduced, and they have no effect on platelet function.

#### Oral dosage guidelines for commonly used nonopioid analgesics

Drug	Dose (mg/kg)	Interval (hour)	Maximum daily dose (mg/kg)
Acetaminophen	10-15	4	100*
Ibuprofen	6-10	6	40**, #
Naproxen	5-6**	12	24**, #

\*The maximal daily doses of acetaminophen for infants and neonates are a subject of current controversy. Provisional recommendations are that daily dosing should not exceed 75 mg per kilogram per day for infants, 60 mg per kilogram per day for term neonates and preterm neonates of more than 32 weeks of post conceptional age, and 40 mg per kilogram per day for preterm neonates 28 to 32 weeks of post conceptional age.

Fever, dehydration, hepatic disease, and lack of oral intake may all increase the risk of hepatotoxicity.

\*\*Higher doses may be used in selected cases for treatment of rheumatologic conditions in children.

# Dosage guidelines for neonates and infants have not been established.

## **2. Opioids**

### **Weak opioids**

The common weak opioids being used in India are Codeine and Tramadol

Codeine phosphate is used popularly in children for management of chronic pain. However, recent evidence of safety and efficacy problems of Codeine and Tramadol has resulted in their withdrawal from recommendation of its use in Step II WHO ladder. Evidence has shown that there are variable expressions of enzyme CYP2D6 in the biotransformation of the pro-drug causing substantial inter-individual and inter-ethnic variability and variable plasma concentration and active metabolite. Codeine induces severe constipation in children. Tramadol lowers the seizure threshold.

### **Strong opioids**

The following are the strong opioids available in India for use in chronic pain:

- Oral morphine
- Methadone
- Transdermal fentanyl patch
- Buprenorphine

### **Oral morphine**

Oral morphine is the cornerstone of pharmacologic analgesia in children. It is the “gold standard” against which all other opioid analgesics are measured, and is the drug of choice unless there are circumstances that prohibit its use.

- The starting dose of **oral morphine** for opioid naive children aged over six months is **0.2-0.5 mg/kg/dose.21**
- The appropriate dosage should be prescribed **every 4 hours**.

### **Dose considerations for neonates and infants**

Due to differences in pharmacokinetics and pharmacodynamics, neonates, preterm and full term infants warrant special dosing consideration and close monitoring when they receive opioids. Opioids analgesics are the mainstay of treatment for controlling severe

pain in neonates. The starting dose for opioid analgesics in infants less than 6 months of age is one-quarter to one-third the suggested doses. The drug clearance and the analgesic effects of morphine and fentanyl for infants above six months of age resemble those for young adults.

### **Transdermal fentanyl patch**

**Fentanyl** is available as a transdermal formulation and provides an effective and convenient alternative to oral opioids in situations where pain is stable. The assistance of paediatric pain specialists should be sought prior to commencing treatment with this form of fentanyl.

### **Methadone**

Methadone is a strong opioid and it is safe to treat moderate to severe pain in children. It is not used as first line analgesia. **Methadone should only be commenced by practitioners experienced in its use.**

### **Buprenorphine**

It is considered as a weak opioid because of its analgesic ceiling effect. It may be used to treat moderate to severe pain. It is available as sublingual tablets and patches. Sublingual tablets not licensed for use in children < 6 years old.

#### Sublingual tablets

- Duration of action- 6-8 hours
- Available as 0.2 mg tablets
- Not recommended < 6 years old
- Dosage:
  - Child body weight 16–25 kg: 100 microgram every 6–8 hours,
  - Child body weight 25–37.5 kg: 100–200 microgram every 6–8 hours,
  - Child body weight 37.5–50 kg: 200–300 microgram every 6–8 hours,
- Caution with hepatic impairment and potential interaction with many drugs including anti-retrovirals.

#### Transdermal patches of Buprenorphine

- Available as 5, 10, 20 microgram patches, applied every 7 days
- Patches not licensed for use in children.

### 3. Adjuvant analgesics

An adjuvant drug is a drug that has a primary indication other than for pain management, but is analgesic in some painful conditions.

Pain	Drugs
Nerve injury	Tricyclic Antidepressants, Anticonvulsants, local anesthetics
Nerve compression, Bone pain, Head-ache due to raised intracranial pressure	Steroids
Smooth muscle spasm	Hyoscine Butyl Bromide
Skeletal muscle spasm	Diazepam, Clonazepam, Baclofen
Gastritis	Gastroprotective agents
Constipation	Lactulose, Bisacodyl

#### Examples of adjuvant analgesics

Indication	Drug	Formulation	Dose
<b>Classification</b>			
<b>Neuropathic pain</b>			
Anticonvulsant	Gabapentin	Tab 100/ 300 mg	5 mg/kg p.o. at bed time, increase q12h than q8h till effective analgesia (max 60 mg/kg/day)
	Pregabalin	Cap 50/ 75 mg	
	Carbamazepine	Tab 100/ 200/ 400 mg; Syp 100 mg/ 5mL	3–10 mg/kg q8h
	Clonazepam	Tab 0.25/ 0.5/ 1 mg	0.01–0.03 mg/kg/day q8h–q12h. Max dose 0.2 mg/kg/day
	Amitriptylin	tab 10mg, 25mg	2-12 yrs: 0.2 mg/kg at night (max 10 mg). >12 yrs: 10 mg at night. Slowly increase every 3-5 days upto 1 mg/kg q12h (max 75 mg/day)
<b>Anxiety, muscle spasm</b>			
Benzodiazepine	Lorazepam		0.025–0.05 mg/kg q6h, max 2 mg per dose

	Alprazolam		Dose not established < 18 years. Start 0.25 mg OD
<b>Tumor compression, raised intracranial pressure</b>			
Steroids	Dexamethasone		0.1 mg/kg q8h, increase upto 1.5 mg/kg/day
<b>Depression</b>			
Tricyclic antidepressant	Imipramine		0.5 mg/kg q8h initially. Increase by 1–1.5 mg/kg/day to a maximum of 5 mg/kg/day

### **Non-pharmacological interventions in the management of pain**

A range of physical therapies may be of use to the child in pain. Touch, massage warmth, cold and electrical therapies are all used in the management of various types of pain. Children may be greatly empowered and assisted by the use of complementary techniques such as acupuncture, guided imagery, relaxation training, meditation and distraction (stories, videos, music, bubble blowing, singing).

### **Resources**

1. WHO guide(2018)- Integrating Palliative care and symptom relief into Pediatrics
2. WHO Guidelines on the Pharmacological treatment of persisting pain in children with medical illnesses (2012)
3. A recommended resource for parents is the Fact Sheet: As Death Approaches: <https://intermountainhealthcare.org/ext/Dcmnt?ncid=522416732>
4. [www.kidsgrief.ca](http://www.kidsgrief.ca)
5. Standards of Practice for Paediatric Palliative Care and Hospice, NHPCO

# Module 5 b : Palliative Care for elderly

## Concepts and definitions

### a) Elderly

Elderly or old age consists of ages nearing or surpassing the average life span of human beings. The policy defines 'senior citizen' or 'elderly' as a person who is of age 60 years or above.

### b) Ageing

Usual aging refers to changes due to the combined effects of the ageing process and of disease and adverse environmental and lifestyle factors-(The Merck Manual of Geriatrics)

c) **Gerontology** is Multidisciplinary and is concerned with physical, mental, and social aspects and implications of ageing.

d) **Geriatrics** is a medical specialty focused on care and treatment of older persons.

### Why is it that the elderly need special care?

Old age is a sensitive phase; elderly people need care and comfort to lead a healthy life without worries and anxiety. Various issues affect the lives of senior citizens and further complicate into major physiological and psychological problems.

### The dimensions of the old age problems:

#### *Physical, economic, social, emotional and spiritual*

- The burden of morbidity in old age is enormous.
- Non-communicable diseases are extremely common in older people irrespective of socio-economic status.
- Disabilities are very frequent
- The problems with functionality in old age compromises the ability to pursue the activities of daily living.
- About 65 per cent of the aged have to depend on others for their day-to-day maintenance

### a) Health problems

- Age related changes in the body and increased physical vulnerability
- Diminishing body reserve
- Multiple diseases due to aging and degeneration risks in geriatrics



- Prone for infections, for injuries, psychological problems and degenerative disorders
- Need special assistance
- Increased risk for disease, disability, and death

#### **b) Psycho behavioural problems**

- Emotional problems, Dementias, Alzheimer's disease, feeling of being devalued

#### **c) Socio economic problems**

- Loss of income, growing medical expenses, skewing effect in allocation of resources, widowhood, loneliness, neglect, and abuse

#### **d) Spiritual issues**

- Coping with losses, meaning of life, death and after concerns
- Treated like an object without respect
- Wishes not honoured
- Loss of control over body functions
- Dying in pain /isolation/alone
- Loss of purpose /meaning

#### **Spiritual challenges**

- Old age is a time of many challenges. Retirement brings opportunities, but for many people it also results in loss of role and income.
- Loved ones may die, leading to the need to grieve and reconstruct life, sometimes without a partner of many years.
- In advanced old age, physical and mental frailty may lead to further loss of role and greater dependence on others.
- Many older people cope well with these social, psychological, and physical losses.
- They do so using personal resources developed over many years, resources that can aptly be described as "spiritual".
- This term is distinct from religion since it embraces people of all faiths and those without any religious faith.

- Broadly, it covers what gives life meaning, purpose, hope, connectedness, and a sense of value.
- Spiritual issues usually surface in the End of Life (EoL) phase
- What should be remembered is that not all are religious, but all are spiritual
- They tend to have troubling questions of transcendental nature about meaning, value and relationship
- The physician's own belief system whether spiritual or religious should not affect the clinical decision making knowingly or unknowingly

## **Health promotion and risk reduction in older adults:**

Various risk factors and their ill effects in elderly people have been identified

### **1. Nutrition**

1 a) Over-nutrition leads to the commonest health problem in old age that is obesity and is associated with hypertension, ischemic heart disease (IHD), and diabetes.

1b) Under-nutrition is equally harmful leading to frailty, physical dependence, and premature health apart from impairment of the immune system, increased risk of infection and poor wound healing.

1c) Common nutritional deficiencies in the elderly include iron, fiber, folic acid, vitamin C, calcium, zinc, riboflavin, and vitamin A.

*Preventative measures to follow:*

- It should be ensured that older people are eating nutritious food.
- Their diet should be planned, and food should be well cooked so that it could be easily digestible.
- They should have access to food that is tasty and easy to prepare.
- A healthy diet varies widely depending on the availability and cultural acceptability of foods.

### **2. Exercise**

Due to ageing, there is a continuous decline in power and strength, and this affects skeletal and cardiac musculature. A sedentary lifestyle and lack of physical activity accelerate

these changes and are associated with a higher risk of morbidity and mortality

The following care should be taken for elderly people:

- Physical exercise should be carried out at a frequency of 3 to 5 days per week, between 20 to 30 minutes per session, to achieve the maximum heart rate.
- Several types of physical exercises are available. The older person should be advised to choose the one which is enjoyable, easy to perform, convenient, and inexpensive.
- Considering all aspects, brisk walking and stretching exercises seem to be the best for older individuals.

### 3. Smoking

- Smoking increases the risk of developing several diseases, such as chronic obstructive pulmonary disease (COPD), coronary heart disease, stroke, and peripheral vascular disease, all of which can potentially have negative effects on people's physical, psychological, and social health in old age.

### 4. Accidents

The elderly is vulnerable to accidents and injuries and are associated with pain and trauma of injury, loss of function, prolonged immobility and its complications; fear of future accidents and self-imposed isolation; and loss of independence. Burns and falls are the most common among accidents and injuries. A large number of accidents can be avoided by taking the following steps

- Use of walking aids
- Optimize the senses:
  - Use of visual aids
  - Use of colors to enhance the older person's vision and depth perception;
  - Use of hearing aids
- Exercise regularly to improve gait and power.
- Gait and balance training to improve coordination and reduce the risk of falls

- Environmental modifications to suit older adults:
  - Removal of obstacles and clutter at home
  - Ensure adequate lighting in the house hold area
  - Use of flat shoes
  - Availability of stable structures to hold on to, in case of an impending fall
  - Proper flooring inside the home and the immediate outside environment.
- Keep floors free of obstacles and moisture.
- Placing non-slippery mats on the floor of the bathroom.

### Screening in the elderly

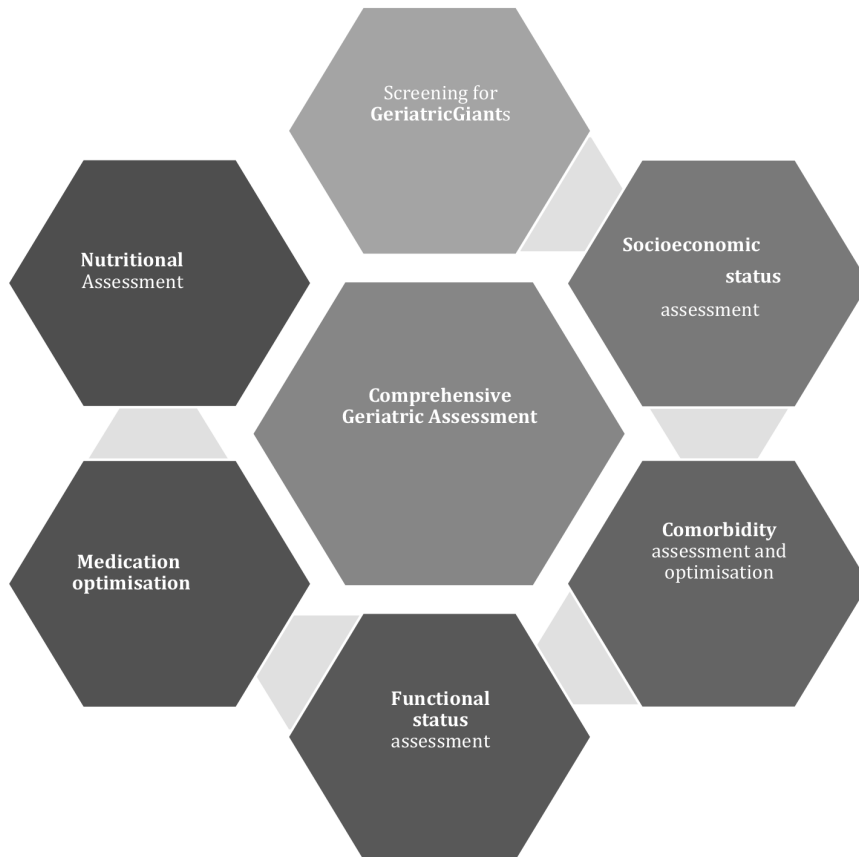
Early diagnosis and treatment are an important step in the secondary prevention of disease and disability. So regular screening for common, life-threatening, and disabling diseases is important for health promotion.

Older adults with **more than three of the following red flags** would benefit significantly from a Comprehensive Geriatric Assessment (CGA). (Annexure 1)

1. Age >75 years old
2. Needs help with Activities of Daily Living (ADLs)/ Instrumental Activities of Daily Living (IADLs) by caregiver
3. Lives alone
4. History of falls
5. History of delirium/confusion
6. History of incontinence
7. More than 2 admissions to acute care hospital per year
8. “Failure to thrive”

## Dimensions of geriatric assessment

Geriatric assessment focuses on the following four dimensions: Physical health; Functional status; Psychological health, including cognitive and affective status; and Socio-environmental factors.



## Comprehensive health care of elderly

### Principles of geriatric care

Care of the older adults differs from that of younger patients with regard to clinical decision making, clinical presentation, diagnosis, evaluation and even with desired outcomes.

### Key phenomena

1. Individuals become more dissimilar as they grow old.
2. Abrupt decline in any system is always due to disease and not due to normal ageing.

3. Ageing is accentuated by disease and attenuated by modification of risk factors
4. The Iceberg phenomenon: The presenting complaint is very often the *tip of the iceberg* and it often hides a multitude of underlying clinical conditions. Eg. A patient presenting with history of fall, may on evaluation be found to have dyspnea on exertion, leading to syncope due to hidden underlying congestive cardiac failure.
5. Weakest link: a new disease manifests itself through organ systems made most vulnerable by previous disease or alterations.
6. Multiple pathology: The universal principle of clinical diagnosis—the law of parsimony where multiple symptoms lead to a single unifying diagnosis, often taught in clinical medicine does not apply to the evaluation of older adults. Multiple complaints often result from multiple co existing diseases and cannot often be attributed to a single diagnosis.
7. Missing symptoms - Eg., Angina/myocardial infarction in an older adult with osteoarthritis- may not manifest with chest pain, but may instead present as confusion, leading to late presentation as pulmonary edema secondary to congestive cardiac failure.
8. Masking of symptoms - Eg., History of fall and fracture of the neck of femur in an elderly female may mask a co existent hemiparesis due to an internal capsule infarct.
9. While younger patients always desire for cure and increased survival, older patients often choose comfort, independence, and preserved cognitive function over increased survival or cure. Hence it is important to determine the patients' goals of care before embarking on major treatment regimens which may cause more distress than benefit.
10. The chief complaint, which is the corner stone of history taking in younger patients loses much of its relevance in older adults. Chief / presenting complaints in older adults are vague, and nonspecific.
11. Disease presentation in older adults is atypical. Example: Urinary tract infection presents with confusion, incontinence, rather than with fever or dysuria. Nonspecific presentation maybe the earliest or only presentations in older adults. Onset of altered mental status, weight loss, fatigue, falls, dizziness, and fever are the most common atypical presentations seen in older adults. Adverse consequences of diseases are more frequent in older adults. Prevention of diseases is much more productive than its treatment. Eg, Vaccination (Pneumococcal,

Influenza), treatment of hypertension and Transient Ischemic Attack (TIA)- more cost effective and lifesaving than treating pneumonia, myocardial infarction and stroke

12. Diseases manifest at an earlier stage (but patients often present late)
  - a. Due to impaired physiological reserve
  - b. Mild disease stage tips the balance
  - c. Despite early symptoms, older adults seek health care much later
13. Small interventions produce dramatic results.

### **Psychological issues in elderly**

Psychological issues in elderly are slowly being realized as an area of immense importance not only in terms of QoL but also in terms of mortality and morbidity. There is a close interlink between multiple physical ailments suffered by geriatric population and their psychological issues.

### **Common psychological issues in elderly population**

#### **Depression:**

Depression is one of the common psychiatric ailments seen in older individuals. Depression in elderly is also associated with poor quality of life, premature mortality, multiple morbidity, cognitive impairment, and difficulty in performing the activities of daily living.

#### **Management of depression in elderly:**

In the treatment of depression in elderly individuals, psychotherapy and pharmacotherapy are the mainstay.

#### **Non-pharmacological approach:<sup>(12)</sup>**

Since elderly individuals are prone to develop adverse drug reactions and drug interactions, non-pharmacological approach should be tried first. This is especially true for mild depression.

#### **A. Psychotherapy:**

If there is no improvement after psychotherapy for about 4 to 8 weeks, then one needs to review assessment, explore additional stressors, review treatment plan, and consider adding or substituting with pharmacotherapy.

## **B. Improving social and family support:**

Family plays a crucial role in supporting an elderly individual with depression. Creating social support helps the individual to cope better and feel valued.

Families must be trained to look for suicidal ideations and report promptly. Their help in ensuring drug compliance is crucial.

## **C. Lifestyle approaches:**

Following a regular routine, exercise, walks, socializing, cognitive engagement and pursuing interests / hobbies have positive effect on depressive symptoms. Spirituality and religious beliefs may offer protection against mental illnesses. Additionally, involvement in faith-based groups improves connectedness and engagement.

## **D. Pharmacotherapy:**

### **To remember while prescribing anti-depressants in elderly individuals**

*(Adapted from Clinical Practice Guidelines for Management of Depression in Elderly. Avasthi A, Grover S)*

- Elderly are more sensitive to a given drug concentration
- The body organs of elderly have decreased capacity to adapt
- Starting dose of an antidepressant must be lower (one third to half) for elderly compared to the starting dose used in young adults
- Since the half-life of most of the antidepressants increase with age dose titration and dose escalation needs to be done with caution.
- Elderly requires longer duration to achieve a steady plasma state
- Side effects related to dose or concentration will take longer to resolve
- There is progressive loss of functional body tissues at the cellular level
- Homeostatic mechanisms that function via central and peripheral feedback mechanisms are altered in the elderly and make them more susceptible to sideeffects



## **Anxiety in the elderly**

Anxiety disorders often co-exist with depression in elderly. Anxiety in elderly can severely impair their quality of life. It can limit their mobility, social interaction, enjoyment, and sense of well-being.

In the management of geriatric anxiety, non-pharmacological approach is recommended first before initiating pharmacological therapy.

### **Life-style modifications:**

#### **A. Exercise:**

Exercise in moderation that is appropriate for an individuals' functional ability is helpful. Walking outside or in the park at a pace that an individual can tolerate will be sufficient. The elderly who are too frail can try walking within the home with support and supervision. Bedridden and wheelchair bound individuals can do simple stretching, flexion and extension exercises.

#### **B. Diet:**

- Deficiency of vitamins B1, B6, B12, and folic acid can be mistaken for anxiety disorder.
- Similarly, alterations in the serum electrolytes can cause anxiety symptoms.
- Discussing the importance of nutritious diet and planning and following a diet chart with balanced nutrition may be the only intervention required in some elderly individuals with anxiety.(14)

#### **C. Sleep:**

Sleep and anxiety are strongly linked. Anxiety can cause sleep onset insomnia.

- Sleep hygiene education can promote good sleep.
- This includes, avoiding frequent day time nap, late evening exercises, late heavy dinner, reducing intake of stimulants, reducing ambient noise and controlling other environmental factors that disturb sleep.
- As the sleep architecture changes in the elderly, the night time sleep decreases. This should be adequately explained to the elderly to reduce expectations and disappointments.
- Guided imagery is useful in preventing anxious thoughts that prevents sleep onset.

#### **D. Relaxation techniques:**

- Jacobson muscle relaxation technique or progressive muscle relaxation technique can be taught to elderly with anxiety. This technique involves tightening (5 seconds) and relaxing (10 seconds) the specific muscle groups sequentially.
- This technique can be combined with mental imagery and breathing exercises.

#### **E. Mindfulness:**

Mindfulness involves focusing on now. There are several ways of practising mindfulness, such as walking outside, looking through a window, doodling, brewing tea, staying away from phone, journaling etc. The idea is to notice the details like smell, texture, colour, patterns, taste and emotions.

#### **F. Social activities and networking:**

Social interactions and networking maintain connectedness. It is not only an important social stimulus but also improves synaptic connections. Purposeful social connections directed towards common goal not only offer engagement but also focus and direction. Eg., Prayer gatherings, book clubs, social tasks etc.

#### **Pharmacological management: <sup>(14)</sup>**

- Consider following principles in the pharmacological management of anxiety disorders.
- SSRIs are the first line of choice
- Always start low, go slow, titrate upward, usually up to the half of adult dose
- When SSRIs fail, then move to other groups (SNRIs, TCAs)
- Always monitor for hyponatremia and bleeding manifestations when SSRIs and SNRIs are used.
- Avoid using benzodiazepines as much as possible. When used, limit use to 2 to 4 weeks. Benzodiazepines have neuro-cognitive effects, can cause confusions, dissociative phenomena and also increase the risk of fall.

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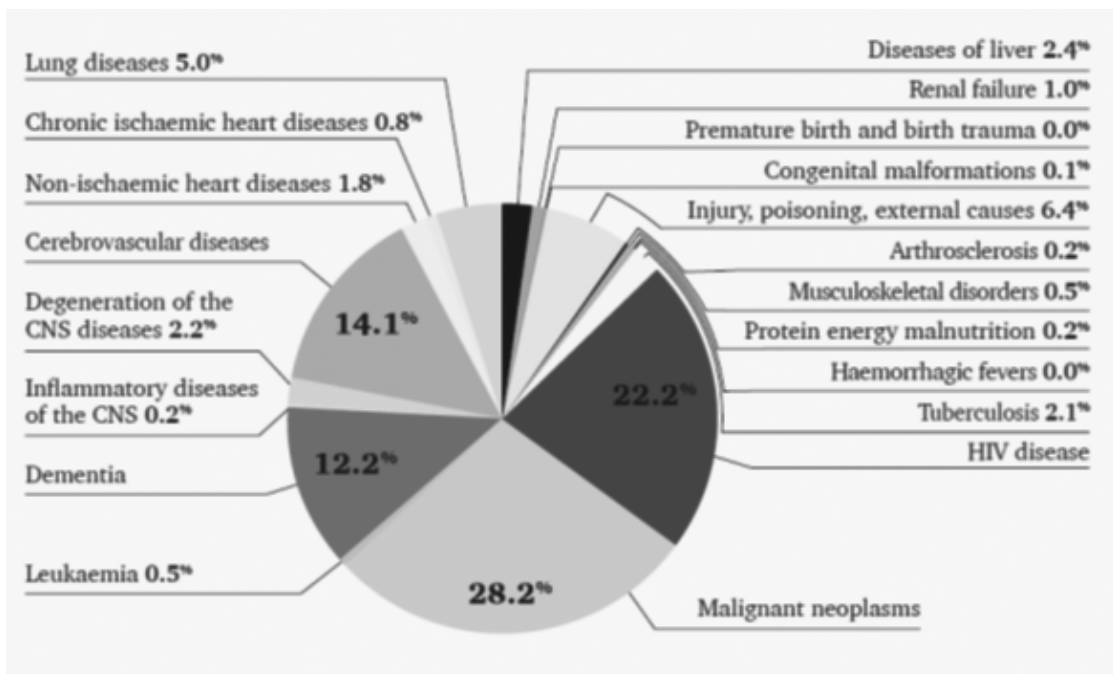
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## **Palliative care for non-malignant conditions**

1. Chronic non cancer illness, such as heart failure, chronic kidney disease, chronic obstructive pulmonary disease, and a likely increase of dementia, are associated with high healthcare use, symptom burden, disability and reduced quality of life.
2. There are similarities between the symptom burden at any time, of patients dying of cancer and those dying of non-malignant cardiorespiratory disease.
3. People with advanced non-cancer conditions may have prolonged multi-dimensional needs, which can be as urgent as those of people with cancer.

4. Decreased functional capacity of patients with advanced non cancer illness places a significant burden on both patients and family members and can lead to increased cost of care.
5. Many studies have shown that symptom burden in patients with advanced non cancer non-communicable diseases are as high as in patients with advanced cancer.
  - a. Patients with End Stage Renal Disease, End Stage Heart Failure, Chronic Obstructive Pulmonary Disease, and cancer suffer from similar symptom clusters.
  - b. Non-cancer patients have higher breathlessness scores, whereas cancer patients have more pain.
  - c. The cancer and non-cancer patients have similar degrees of depression and fatigue.
6. In many places, palliative care is directed at people with cancer, while people dying of non-malignant disease have little or no access to such care.
7. This may be because of difficulty in establishing an exact prognosis for people with non-malignant disease, difficulty in identifying a 'terminal phase', or poor understanding of the needs of people with non-malignant disease.
8. The typical model of cancer palliative care covering the relatively short incurable illness phase might not suit people who have a gradual, progressive decline with unpredictable exacerbations.
9. Uncertainty about prognosis should not result in the needs of these patients, and their families, being neglected by health and social services.
10. The starting point for palliative care in patients with non-cancer conditions may be identified through symptom assessment.
11. Palliative care teams, through offering advice and sharing care with other specialists, can improve the care of many non-cancer patients.
12. Worldwide need for Palliative Care for adults ( Global Atlas of Palliative Care 2020)



#### Barriers to offering palliative care services for non malignant conditions

1. Lack of awareness and training. Inadequate education and training for health care professionals
2. Issues related to regular predictable availability of essential medicines required, particularly in the peripheral units
3. Lack of availability of basic manpower and other resources (infrastructure, logistics)
4. Psychological, social, cultural, and financial barriers

## Module 6 : Nursing issues

### Pressure sores

Pressure sores are pressure-induced ischemic soft tissue injury. It is characterized by a localized area of tissue necrosis. It occurs when the skin and soft tissue beneath is compressed between the bony prominence and the external surface. When the pressure in between the two compressing surfaces exceeds the capillary pressure, the blood supply is cut off resulting in ischemia and injury. In addition to the pressure-induced ischemia, friction and shear add to the injury. The pressure injuries usually develop if the pressure is sustained for about 1 to 4 hours.

Pressure sores are seen often in pressure points.

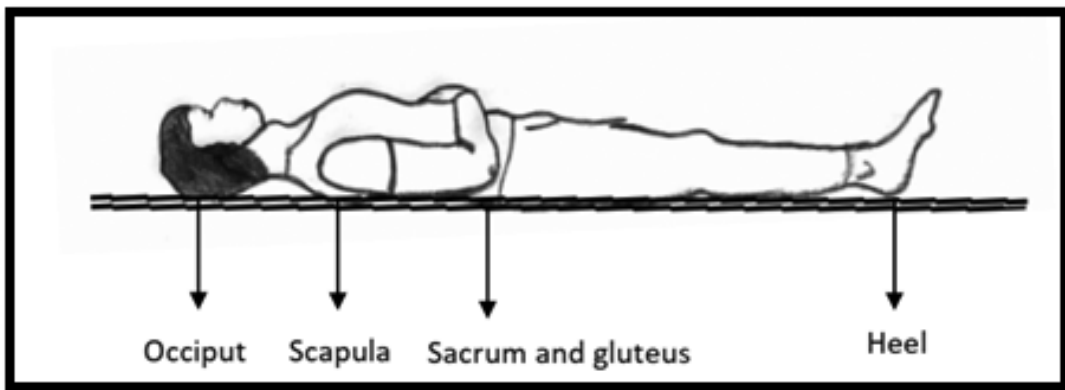


Figure 1: Pressure points in the supine position

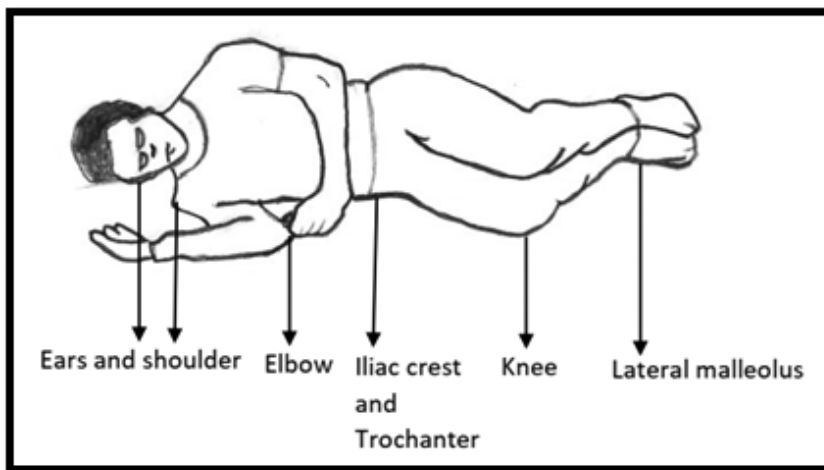


Figure 2: Pressure points in the lateral position

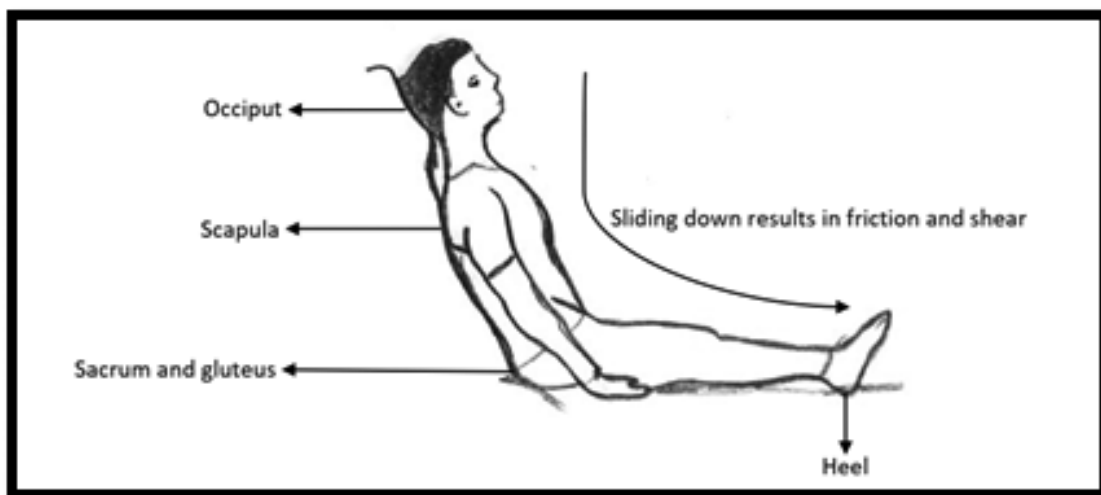


Figure 3: Pressure points in sitting position

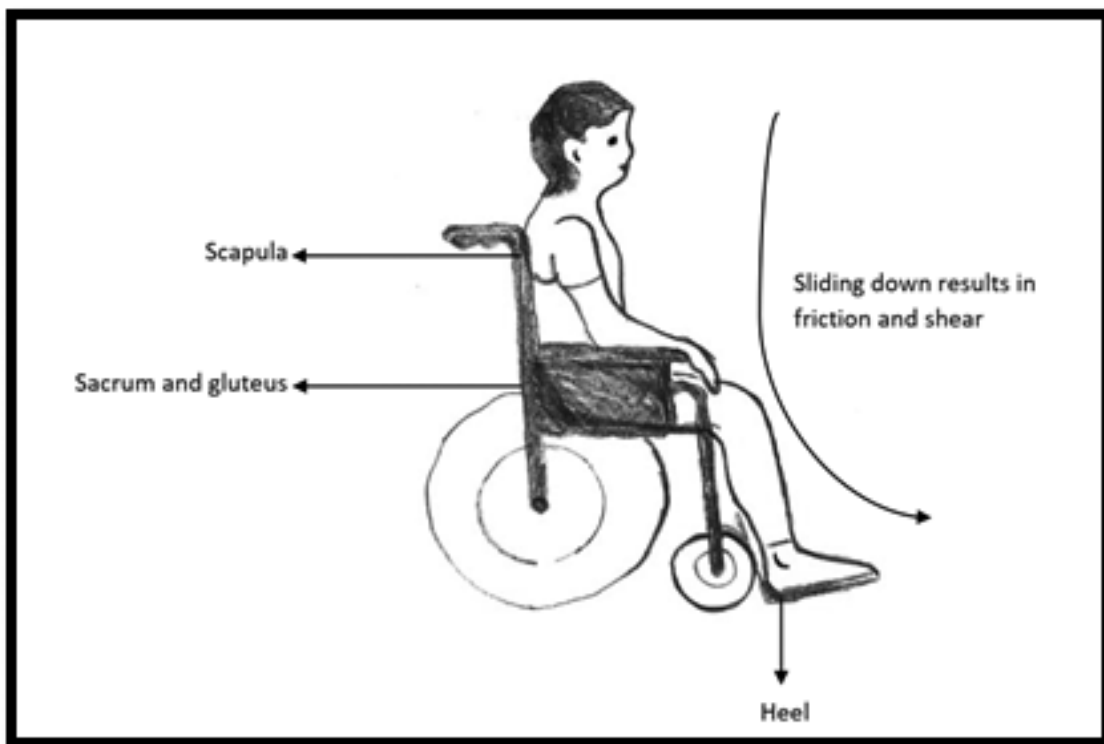


Figure 4: Pressure points in sitting position

In prone position breasts in females and genitalia in males are areas susceptible to pressure ulcers.



## Who are at risk of developing pressure sore?

1. Age. Older adults have thinner skin, less natural cushioning over bones, and poor nutrition
2. Lack of pain perception. E.g.; Spinal cord injuries
3. Malnutrition
4. Urinary or faecal incontinence. Moist skin can break down easily. Bacteria from faecal matter can cause infections
5. Comorbidities: Disease conditions affecting circulation (diabetes mellitus, vascular diseases) / Smoking (Nicotine impairs circulation and reduces the amount of oxygen in the blood)
6. Decreased mental awareness by disease, trauma, or medications E.g.: CVA
7. External devices E.g. Cast

## Prevention and management of pressure sores:

### Position change:

To protect the patient from developing pressure sore and also to promote healing for the patient who has already developed pressure sore, periodic and regular position change is crucial

- For a patient who is lying, his/her position should be changed every 2 hours
- For a patient who is sitting/confined to a wheelchair, the position must be changed every 15 minutes

### Support surfaces:

Air bed and water bed are effective in reducing the pressure exerted on the bony prominences but they are not a substitute for position change. These special mattresses distribute the pressure throughout the body thereby reducing the pressure on bony prominences. Head rings can be used to reduce pressure at the occiput, but they should be used intermittently with caution. Gloves filled with water can be placed below the achilles tendon to prevent pressure injury at the heel. In addition to the use of special surfaces, wrinkle-free bedding materials are important in preventing superficial skin abrasions.

### Nutrition:

Patients with long-term pressure ulcers are in a chronic catabolic state. These patients often suffer from hypoalbuminemia, especially in those with excessive wound discharge. To support wound healing these patients require 30 to 35 Cal/kg/day energy and 1.5g/kg/day of protein.

### Management of incontinence:

The presence of urinary incontinence increases the risk of developing a pressure sore by several folds and an existing bedsore is unlikely to heal in the presence of incontinence. Faecal contamination of the pressure sore will produce infection, delaying wound healing. Both urinary and faecal incontinence needs to be managed aggressively to promote healing. Faeces needs to be removed and the perineum needs to be cleaned immediately after the defecation. Cleaning the area with warm water promotes comfort and circulation. Urinary incontinence can be managed by condom drainage (males) or indwelling catheter in chronic conditions, but in the end of life care, non-invasive interventions are preferred.

### Exercise:

Exercise is often ignored in bedridden patients. These patients lose their muscle mass due to inactivity resulting in more prominent pressure points. The progression of pressure sore is faster in patients with poor muscle mass. Active and passive exercise helps in maintaining muscle mass. Daily exercises also promote circulation, greatly reducing the risk of developing pressure sores.

### Hygiene:

Bedridden patients are more susceptible to skin infections. Fungal infection can quickly develop due to moisture. Maintaining clean and dry skin is crucial in preventing pressure sores. Using emollients on the skin regularly reduces friction exerted on the skin. Daily back care and bed bath with warm water promotes circulation, promotes comfort, and reduces the risk of developing pressure sores. While providing skincare, vigorous massages should be avoided on the bony prominence and reddened areas as they may produce deep tissue injuries. Performing these procedures daily also facilitates assessment for skin changes.

### Controlling infection:

The diagnosis of wound infection is a clinical diagnosis and not a microbiological diagnosis as almost all the wounds are colonized by bacteria. The following are the signs of wound infection.

- Erythema around the wound
- Increased warmth
- Increased tenderness
- Foul-smelling, thick, purulent discharge
- Fever

Metronidazole powder is very effective in controlling wound infection. It is effective against both gram-positive and gram-negative organisms. Metronidazole works effectively against foul smell producing anaerobic organisms. Daily dressing the bedsore with saline and metronidazole tablets crushed into powder (or gauze soaked in metronidazole IV solution) can effectively treat the infection.

## Malignant fungating wound

### Sufferings of a patient with a chronic, non-healing malignant ulcer:

It is important to keep in mind that a person with a chronic, non-healing malignant ulcer suffers physically, psychologically, socially, and spiritually. It affects all domains of life. Understanding this helps us focus our interventions addressing each domain. Only this kind of holistic approach improves the quality of life of patients with a chronic, non-healing malignant ulcer.

### Physical problems:

**Pain:** Chronic ulcers produce chronic pain and problems associated with chronic pain. Malignant ulcers especially have the tendency to infiltrate adjacent tissues, nerves, and bones. So, a patient with a malignant ulcer may have a combination of nociceptive and neuropathic pain.

**Bleeding:** Bleeding is a worrisome problem with malignant ulcers. Because of the neovascularization of a malignant tumour, these ulcers have the tendency to bleed and are often difficult to manage.

**Exudate:** Malignant wounds produce excessive exudates due to vascular permeability of the tumour. Not all exudates are of infective origin. The presence of purulent exudate points to an infection. In non-malignant ulcers, excessive exudates can be seen in venous ulcers.

**Malodour:** The cause of malodour is multifactorial. Both gram-positive and gram-negative infections cause malodour, but gram-negative infections produce an excessive foul smell. Necrotic tissue and heavy exudates also produce malodour. The presence of

the dead, necrotic tissues in the wounds makes it suitable for bacteria to colonize, which results in further tissue destruction and production of foul-smelling exudates. Malodour causes severe distress to the patients and the family. It affects the appetite, interferes with sexual function, restricts social interaction, and leads to isolation. Assessment of malodour needs to be carried out sensitively.

**Pruritis:** Pruritis in a malignant fungating wound is caused by stretching of the skin. This excessive stretching causes nerve irritation. Dryness of skin adds to the problem. This pruritis usually does not respond to anti-histamines.

**Maggots:** It is the most devastating and frustrating problem seen in chronic non-malignant and malignant wounds. It is caused by poor wound care. When the wound is left open the flies lay their eggs in them, producing maggots. Though maggots eat only the dead tissue, their movement causes pain and the sight of worms in the wound is very distressing for the patients and the family.

### **Psychological problems:**

**Frustration:** The non-healing and delayed healing nature of chronic ulcers causes frustration to the patients and their families.

**Anger:** Frustration leads to anger and resentment.

**Anxiety:** Anticipating the pain during dressing is an important cause of anxiety, which should be addressed effectively.

**Depression:** Patients with chronic wounds often suffer from depression. Hopelessness, family isolation, and social isolation may be important in the development of depression.

**Body-image issues:** When the ulcer is in a place that is visible to others (Face and oral cavity) or sensitive private body parts (e.g. breast, genital areas, etc) sense of shame can be significant. This can have both psychosocial (depression, anxiety, avoidance) and medical consequences (e.g. treatment avoidance).

**Sexual problem:** Chronic pain due to chronic ulcers decreases libido. This is exponentially worsened by a foul smell, discharge, family conflicts, and spousal dissatisfaction. Unless explored, the sexual problems in patients with chronic ulcers go unnoticed.

### **Social problems:**

Isolation within the family: A patient with a malignant fungating wound often gets confined to a dark corner in the house. Children may avoid visiting that room and family members may enter the room only to bring food, water, and do dressing. “Normal Life” happens outside the room. Families often do this to protect the patient without any malicious intent. But this completely isolates the patient from the family and they feel

alienated.

**Isolation from society:** A patient with an ulcer is usually afraid of going out of the house. Fears like “What if someone accidentally hits me when I am travelling in the bus?”, “what if the dressing comes off?”, “Will others be uncomfortable because of the foul smell?” These fears are genuine and result in poor social interaction. They stop attending family functions, avoid social gatherings, and isolate themselves.

**Financial problems:** The financial burden of caring for a chronic wound can offset the family equilibrium, especially when the person suffering from the chronic wound is the breadwinner or when the patient is required to visit the hospital every time for dressing. Loss of wages, loss of time, and other health care expenditures push the family into poverty.

**Spiritual problems:**

The spiritual distress in a person with chronic wounds can manifest as guilt, loss of faith, questions like “where is God?”, “why me?” and “have I been forsaken?” The inability to perform some religious rituals may cause fear and frustration in some patients. In some patients, suffering may make them more spiritually active and engaging.

**Principles of management of fungating wound:**

- Promote comfort
- Build confidence
- Prevent isolation
- Improve the quality of life

**Management of ulcers in a home setting:**

It is neither realistic nor ideal for a patient with a non-healing ulcer to go to the hospital daily for wound care. We aim to empower the patients and family caregivers to care for the wound in the home setting while we, the professional caregivers play a supportive enabling role. Through home-based wound care, we can minimize health-related expenditure for the family and enhance their quality of life.

**Home preparation of dressing material:**

1. Saline can be prepared at home by adding one pinch of salt in one glass of water or one teaspoon of salt in one litre of water and boiling it for 20 minutes. The saline prepared this way is for one-time use only. It should be prepared as and when needed.

2. Dressing material can be prepared by cutting soft cotton cloths into small pieces and steaming them in a rice cooker / pressure cooker. To maintain their sterile nature, clothes treated this way should be used directly from the vessel (after allowing to cool down).
3. They can be stored in a clean container but they are no longer considered sterile but can be used within 24 hours
4. Metronidazole tablets (plain) can be given to the family to be powdered and stored. If IV Metronidazole is given to the family, instructions should be given on opening and using the bottle correctly.

### **Management of common problems in fungating wounds**

#### **Management of incident pain:**

In this case, it refers to the pain while doing dressing. (Procedural pain)

1. Incident pain can be managed by administering the rescue dose of analgesic half an hour before dressing or timing the dressing half an hour after the regular dose.
2. Ketamine can be given sublingually as 0.25-0.5mg/kg, 15 minutes before dressing. The same drug used for injection is given sublingually.
3. It is crucial to completely wet the dressing before removing it from the wound. Removing a dry dressing causes additional injury, bleeding, and pain.
4. Non-adherent dressing like paraffin gauze is less painful on removal. But they cannot be used in the presence of active infection.
5. Bupivacaine ( localanaesthetic) gauze soaking reduces pain when applied before dressing
6. Metronidazole powder can be mixed with lignocaine jelly to make a paste to minimize the pain.

#### **Management of bleeding:**

Bleeding is more pronounced in malignant ulcers. For this reason, mechanical and sharp debridement is avoided. The following measures can be taken to stop and prevent bleeding.

1. Avoid removing the dry dressing. Always wet the dressing before removal.
2. Meticulous care should be taken while dressing wounds with a tendency to bleed
3. Non-adherent dressing like vaseline gauze dressing can minimize injury while removing the dressing and reduce the risk of bleeding.

4. Pressure bandaging with additional pads helps in compressing the bleed
5. Minor bleeding can be controlled using sucralfate powder dressing or calcium alginate dressing if available
6. In case of profuse bleeding, compressing the wound for 10 minutes with gauze soaked in adrenaline (1:1000) helps in controlling the bleeding. This should be used with caution as there are chances of rebound bleeding once the effect of adrenaline wears off. There is also a risk of avascular necrosis.
7. For nasopharyngeal bleeding, tranexamic acid mouth wash can be done twice daily. The solution is prepared as 5 grams of Tranexamic acid (injection) in 50mL of warm water.
8. A systemic anti-haemorrhagic agent like ethamsylate and fibrinolytic antagonists like tranexamic acid may help prevent bleeding.
9. Bleeding in large quantities that cannot be controlled by these modalities might require a surgeon's intervention.

#### **Management of excessive exudate:**

1. Identify the cause of excessive exudate. If excessive exudate is due to infection, it should be treated with local and systemic antibiotics
2. Peri-wound skin should be protected with emollients as exudates can cause peri-wound skin maceration
3. Additional cotton pads can be used to absorb the exudates. The number of pads will depend on the soaking of external pads and bandage.
4. If exudates are not controlled by additional pads consider the use of absorptive dressing such as charcoal dressing (ideally if ready-made preparation is available; fresh preparation method- use charcoal with padding around it is feasible but can be messy), use hydrofiber dressing and alginate dressing if affordable.
5. If affordable consider the use of Negative Pressure Wound Dressing (NPWD) with a suction apparatus at home.

#### **Management of wound maggots:**

Maggot infestation happens when the wound is left open and not cared for regularly. So, it is very crucial to re-emphasize the importance of cleaning the wound regularly and covering the wound with a dressing.

## **Different methods for maggot removal:**

Ensure the availability of hot water in a small vessel to kill the maggots upon their removal.

Mechanical removal and irrigation: Maggots present in the shallow area can be mechanically removed with a forceps or a damp gauze and the wound irrigated with saline.

Suffocation: Maggots require oxygen to survive. So, maggots can be suffocated to death by applying paraffin ointment or three paraffin gauzes over the wound bed to block air circulation for 24 hours. Dead maggots can be manually removed or they will be broken down by the macrophages and subsequently washed during the regular wound care. Metronidazole powder can be added to the wound bed before applying paraffin gauze to inhibit the growth of anaerobic organisms.

Hide and seek technique: Maggots are photophobic. They tend to hide into the crevices when exposed to light. So, a gauze or pad can be used to close the wound bed for 30 to 60 seconds. This encourages the maggots to move back to the wound bed and they can be quickly removed with a forceps or a moist gauze.

Using turpentine oil: Turpentine should be used with great caution as it can cause skin burns. It can be used to remove maggots hiding deep inside the wounds. A gauze piece soaked with 2mL of turpentine oil is placed on the wound bed. It is then covered with a large pad for about 5 minutes. The fumes of turpentine will force the maggot to exit from the deeper areas of the wound. They can be picked up with the help of forceps and dropped into the hot water tub.

## **Care of stoma**

### **Ostomy and Stoma:**

Though ostomy and stoma are used interchangeably they have different meanings. Ostomy is a surgery to create an opening (stoma) from inside to outside. Whereas, a stoma is an opening that connects a body cavity to the outside environment. Ostomies based on their purpose, location, duration and number of stomas are classified into several types.

### **Based on purpose:**

- Input ostomies
  - Tracheostomy, Gastrostomy, Jejunostomy
- Output ostomies
  - Ileostomy, Colostomy, Urostomy



**Based on location:**

- Ileostomy
- Ascending colostomy
- Transverse colostomy
- Descending colostomy
- Sigmoid colostomy

**Based on duration:**

- Temporary (Rectal repair)
- Permanent (Malignancies)

**Based on number of stomas:**

- Single barrel colostomy (Ileostomy)
- Double barrel colostomy (Loop colostomy)

**Characteristic features of different output ostomies based on the location:****Ileostomy:**

On an average, patients with ileostomy have an output of 500mL to 1300mL per day and this may go up to 1800mL during initial post-operative period. Since patients with ileostomy lose lots of water which is mainly absorbed in large intestine, they are at increased risk of developing dehydration and renal stones. Thus, it is recommended that the patients with ileostomy should increase their water intake by 500 to 700mL per day. They can also develop electrolyte imbalances as the sodium and potassium loss is more through ileostomy. Since the ileostomy output has higher concentration of digestive enzymes, they can easily develop skin excoriations. The stool is liquid and the output is unpredictable so it is important that the patient always wears the pouch.

**Ascending colostomy:**

Present on the right side of the abdomen. The output is acidic in nature with higher concentration of digestive enzymes. The stool is liquid in nature with unpredictable output hence it is recommended that the patient always wears the pouch.

**Transverse colostomy:**

The stool in transverse colostomy is liquid to semi-formed. Since the output is unpredictable it is recommended that the patient always wears the pouch. Since transverse colostomy is performed in the upper abdomen, concealing the stoma and the pouch can be challenging. The output of transverse colostomy has fewer digestive enzymes hence skin excoriation may occur if there is leakage or if there is no skin protection.

**Descending colostomy:**

The stoma is located in the lower left abdomen. The stool in descending colostomy is semi formed to completely formed. At this point water resorption is complete and there are no digestive enzymes present in the stool. The bowel movement in descending colostomy can be mostly predicted. Occasionally there may be spilling of stool in between evacuation hence it is safe to wear a pouch. Irrigation of stoma is possible with descending colostomy.

**Sigmoid colostomy:**

Patients with sigmoid colostomy have better quality of life compared to people with other ostomies. This is because the stool is fully formed and completely devoid of digestive enzymes. The bowel movement can be predicted. Colostomy irrigation is very much possible with sigmoid colostomy. Some patients may prefer to evacuate without irrigation. Once the colon is loaded with considerable amount of faecal matter above the stoma, reflex will naturally set in and the bowel movement will begin. Some patients may require mild stimulation by drinking tea, coffee, warm water or juice. Once the evacuation is complete these patients need to wear only a small protective pouch.

**Problems faced by patients with colostomy:**Peristomal skin problems:

Normally the peristomal skin should have the appearance and the texture similar to the abdominal skin. Peristomal skin problems are common among patients with stomas. When there is peristomal skin irritation it is crucial to identify the cause. The cause could be of chemical, mechanical or microbiological origin. Sometimes these causes may overlap each other. The proteolytic enzyme coming in contact with intact skin is one of the major sources of skin irritation. The right size of skin barrier around the stoma and application of barrier cream protect and prevent skin irritation. Karaya powder mixed with egg white is very effective in treating skin excoriation. Some patients can be allergic to pouching products. Choosing the right pouching system is crucial in such cases. Mechanical injury occurs while removing the skin barrier. They are characterized by blisters and skin peeling and abrasions. Teaching the patient and the caregivers to gently push the skin around the barrier will prevent mechanical injuries. Microbial infection is common among the patients with diabetes mellitus and immunosuppression. The moisture around the stoma predisposes them to fungal infection. These are characterized by maculopapular rash and satellite lesions. There may be erythema and itching. The patients should be advised to pat dry the peristomal skin and dust antifungal powder to treat the fungal infection.

### Dehydration:

Except in sigmoid colostomy and descending colostomy there is excess water loss through other stomas. These patients are at the risk of dehydration if they do not consume adequate water. It is recommended that they always carry water with them and **'drink little and drink often'**

### Stomal necrosis:

Stomal necrosis is an early complication following surgery. Occurs due to venous congestion and arterial insufficiency. Normal colour of the stoma is bright pink or deep red. Necrosis is more common in those who are obese. A stoma turning blue is a sign of ischemia. When ischemia is suspected the patient should be monitored as they may require surgical revision. A pale stoma is indicative of anaemia.

### Stomal bleeding:

Minor bleeding is common in immediate post-operative period. It can occur due to vigorous handling of stoma. Lacerations while changing the pouch and accidental injuries can cause bleeding. In patients with portal hypertension with varices, delicate handling of stoma is important. Minor bleeding, mostly from granulation tissues around the stoma, can be managed with compression and application of sucralfate powder. If bleeding is not controlled with conventional practices, they will require surgeon's attention and cauterization.

### Stomal retraction:

Stomal retraction is defined as stoma that is 0.5cm or more below the surface of the skin. It can affect pouch adherence, cause leaking and lead to stenosis and obstruction. Patients who are obese, patients with thick abdominal wall and initial stoma length less than 10 mm have more risk of developing retraction. Convex pouch system helps in managing stomal retraction. Ostomy belt or binder in combination with the convex pouching system can straighten the skin folds and enhance adherence of the skin barrier.

### Stomal prolapse:

Stoma prolapse is defined as the telescoping of the stoma more than the normal length. Prolapse is more common in loop colostomies and descending colon colostomies. Prolapsed stoma can cause problems with pouch adherence. The oedema due to prolapse can result in poor perfusion and ischemia. Uncomplicated prolapse without ischemia can be managed with hyper osmotic agents such as sugar or honey to reduce the edema followed by manual reduction by a trained person. This can be further followed up with the application of binder to prevent prolapse. A complicated prolapse will require surgical intervention.

### Stomal stenosis:

Stenosis is defined as narrowing of stoma. Narrowing of stoma can cause difficulties in expulsion of faecal matter. Stenosis can occur as a result of retraction and poor pouching system. Mild stenosis can be managed by avoiding insoluble dietary fibres than can create hard lumps and catheter dilation by an expert. Severe stenosis producing abdominal cramps and forceful expulsion of contents will require surgical correction.

### **Constipation and diarrhoea:**

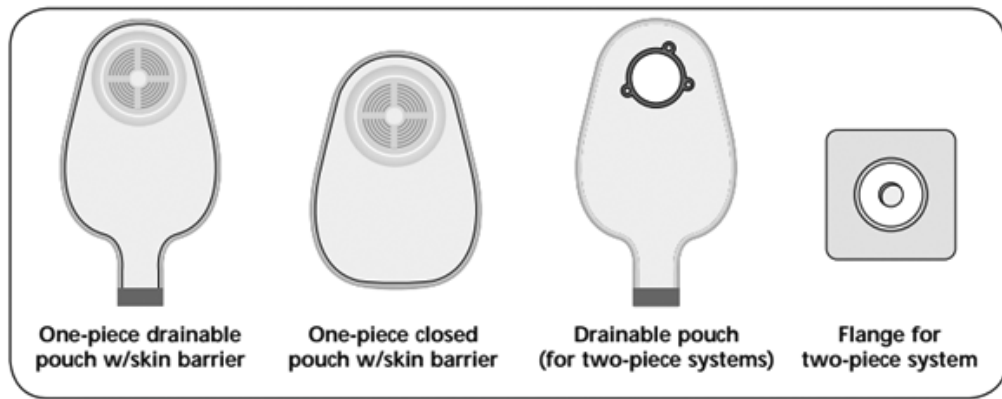
Constipation in patients with ostomy is usually due inadequate water intake. Consuming insoluble dietary fibres can cause temporary obstruction and cramps. Usually constipation can be managed by increasing fluid intake and soluble dietary fibre. An inactive proximal stoma for 4 to 6 hours along with abdominal cramps will require medical attention. Some patients may require laxatives to manage constipation. It is important to differentiate diarrhoea from loose stools that are normally seen in stomas that are more proximal. Diarrhoea could be due to various causes ranging from diet, stress and medications. Sometimes raw fruits, raw vegetables, fruit juices and milk can temporarily produce loose stools and they resolve on their own. Diarrhoea that is of infective origin will require medical management. Since patients with a stoma tend to lose more electrolytes, hydration and replenishing of electrolytes is crucial.

### **Colostomy pouch:**

Colostomy pouches are basically bags that collect stool from the colostomy. In addition to acting as a reservoir, the pouch protect the peristomal skin and prevent the escape of bad odour. It is very important that the patients are empowered in managing the pouch system to have a good quality of life with a stoma.

### **Types of Pouches:**

- One-piece drainable pouch
- One-piece closed pouch
- Two-piece pouch system
- Stoma cap



Stoma pouch system (Credits: United Ostomy Association of America)

There are disposable and reusable pouches in two-piece system. For patients with retraction and skin folds convex flange systems are available for better adherence.

### Changing the pouch and skin barrier:

It is very crucial to avoid mechanical injuries during pouch and base plate change. The safe way to remove the skin barrier is to push the skin gently around the stoma while lifting the skin barrier off. Once the barrier is removed, clean the area with warm water and pat dry the area. Once the area is dry new skin barrier and pouch can be applied. While applying the skin barrier the circumference of the stoma should be correctly measured and the pouch opening should be cut accordingly. The opening should only be 1/8th of an inch larger than the stoma to reduce skin exposure. The pouch should be emptied when it is 1/3rd full to prevent leaking.

- For ileostomy one-piece drainable pouch should be changed once in 1 to 3 days based on the need. For a two-piece drainable pouch, the base plate should be changed twice or thrice a week as per the need and the pouch is to be changed every 1 to 3 days.
- For colostomy one-piece closed pouch will require 1 to 3 changes a day. For two-piece pouch system the base plate needs to be changed 2 to 3 times a week whereas the closed pouch requires 1 to 3 time changes a day.
- For urostomy one-piece pouch system requires change once in 1 to 3 days. In two-piece pouch system the base plate is changed 2 to 3 times a week whereas the pouch is changed once in every 1 to 3 days

### **Diet for patients with colostomy:**

There are no absolute dietary restrictions for patients with colostomy. Some dietary products can be odour producing and gas forming which the patient may have difficulty managing. The patients learn themselves over time to adapt to different dietary products. It is important to avoid time release and enteric coated tablets as they are not absorbed completely. When the patient consumes gas producing food substance the 'lag time' for flatus to pass out of ileostomy is 2 to 4 hours from the onset of eating. For distal colostomy it is 6 to 8 hours.

- Cabbage, garlic, beans and fried food may cause odour
- Corn, nuts, cabbage and vegetable peeling may cause hardening of stool
- Coffee, fruits and fruit juices and oily food may cause loose stools
- Mint, coriander reduces the smell

### **Travel, work, dressing and sports:**

Patients with colostomy can travel like any other person. They may need to carry extra bags if they need to change immediately. Patients can engage in routine works that does not involve heavy lifting and strenuous exercise as the increase in intra-abdominal pressure can cause the stoma to prolapse. The pouch can be comfortably worn underneath the cloths and are easily concealed. It is safe to avoid contact sports that can cause injury to the stoma.

### **Tracheostomy**

**Tracheostomy** is a surgical opening made in the trachea to facilitate breathing. The tracheostomy can be temporary or permanent in nature. In a palliative care setting, the temporary tracheostomy is usually rare.

### **Indications of tracheostomy:**

1. Prolonged intubation/ventilator support and weaning
2. To effectively manage secretions
3. Upper airway obstruction (E.g. Malignant conditions)
4. Airway protection (E.g. Neurological conditions)

### **Type of tracheostomy tubes:**

Tracheostomy tubes are universal. All tracheostomy tubes have the '**Jackson curve**' which is a 'J' shaped curve perfectly angling into the trachea. They come in different sizes

for different age groups and different built of the patient. Some tracheostomy tubes may have additional features such as cuff and fenestration. The tubes may have a single lumen or double lumen. They may be reusable or single-use tubes. Based on the manufacturer and the period of usage they are made from PVC, silicone and metal.

### **Changes in the airway following tracheostomy:**

#### Thickening of tracheal secretions:

When tracheostomy is performed the upper airway is completely by-passed, thus the person loses the warmth and humidification provided by the upper airway to the inhaled air. Absence of warmth and humidification results in the thickening of tracheal secretions that are difficult to remove.

#### Increased risk of infection:

The upper airway not only provides humidification and warmth but also the filtration of inhaled air. Losing this protective mechanism predisposes the person to an increased risk of pneumonia.

#### Communication:

A person with tracheostomy will often have difficulty communicating as the air does not reach the vocal cords but bypassed through the stoma

#### Loss of smell and taste:

As the air does not pass through the nose patients with tracheostomy have a diminished sense of smell. Since taste is closely associated with smell the patients also suffer from diminished taste sensation.

### **Complications following tracheostomy:**

#### Immediate complications:

1. Haemorrhage
2. Aspiration
3. Air embolism
4. Hypoxemia/Hypercarbia

#### Early complications:

1. Haemorrhage
2. Pneumothorax

3. Accidental decannulation
4. Stomal infection
5. Dysphagia

Late complications:

1. Tracheomalacia
2. Tracheoesophageal fistula
3. Granulation tissue formation
4. Aspiration
5. Pneumonia
6. Dysphagia

**Problems faced by patients with tracheostomy and its management:**

Cough:

Cough can be due to excessive secretions, thick secretions and airway dryness. The first line of management of cough is to hydrate the patient well. Hydration helps in loosening the thick secretions and prevent the dryness of mucosal airway. If there are excessive secretions, suctioning them is helpful. Suctioning should be done carefully and prudently. If the excessive secretion is due to infection antibiotic use is warranted.

Secretions:

Secretions are a normal response of the airway to a tracheostomy. The presence of excessive secretions causes discomfort to the patient. If the secretions are thin and loose, they can be coughed out by the patient himself with or without chest physiotherapy. Thick yellow or green discoloration of secretions may be suggestive of infection and will require antibiotics. Steam inhalation can be used to reduce the thickness of the secretions. Temperature more than 41°C can damage the airway mucosa, so one should maintain adequate distance between the stoma and hot steam. Suctioning can be performed to remove excessive secretions. Suctioning should not be done for more than 10 seconds. Thick mucous plug within the inner cannula can be washed with running water.

Communication:

Loss of voice poses a significant challenge to patients with tracheostomy. Losing the voice, difficulty in communicating and not being understood clearly by the family and the professionals leads to frustration. Helping the patient to communicate well early helps in



minimising these effects. Communication can be achieved in patients with tracheostomy without complete upper airway obstruction.

1. Closing the tracheostomy opening with a finger while speaking
2. Speaking valve (Passy-Muir Valve)

Both techniques work by forcing the air to pass through the upper airway by blocking the tracheostomy opening, in patients with functional larynx. In the finger method, the patient is asked to inhale and close the tracheostomy opening with the finger and speak, this forces the exhaled air through the vocal cords into the upper airway producing voice. A speaking valve is a one-way system that opens during inspiration allowing air to enter through the tracheostomy and closes on expiration which forces the exhaled air through the vocal cords and upper airway. Patients may experience fatigue while using a speaking valve because of the effort that is required to push the air into the upper airway. The presence of secretions in the airway will make speaking difficult. So, removing the secretions before speech training is recommended.

#### Eating and nutrition:

Patients with tracheostomy have a decreased sense of smell as the air is breathed through the ostomy than through the nose. Since taste and smell are closely associated these patients also suffer from poor taste. One way of overcoming this problem is 'Polite yawning' or NAIM (Nasal airflow inducing manoeuvre). This is achieved by advising the patient to repeatedly perform yawning with the lips sealed. Lowering the jaw and tongue creates a negative pressure in the oral cavity forcing air into the nose, stimulating the olfactory epithelium. This can be recommended to smell the food before they eat or whenever they want to smell other things.

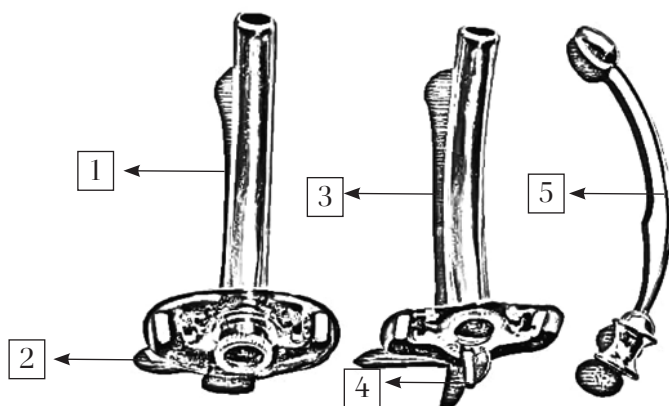
The person may have dysphagia, aspiration and vomiting while eating. Removing tracheal secretions by suctioning or by chest physiotherapy before eating is helpful. This prevents cough while eating as coughing while eating can induce vomiting. Other measures that can help is to sit straight while eating, chewing thoroughly before swallowing and small quantities per bite (<5mL). In patients with severe aspiration problems nasogastric or gastrostomy feeding is recommended.

#### Body image concerns:

Psychological and self-esteem issues following tracheostomy are closely associated with personality traits. Patients suffer from social isolation and role reversal in the family. Sexual intimacy and physical contact concerns affect not only the patient but also the family dynamics. These patients will require repeated assurance and reassurance.

Reducing the problems associated with a tracheostomy is crucial in improving the quality of life. Teaching the patient how to protect the opening and reducing the secretions and communication training will promote confidence and improve social interaction. Counselling the spouse and the patient about sexual issues is important as tracheostomy does not physically interfere with sexual function though psychologically it can have a large influence on sexual function.

### Parts of tracheostomy tubes:



*Metal tracheostomy tube*

1. Outer tube   2. Neckplate   3. Inner tube   4. Inner tube lock   5. Obturator

### Care of tracheostomy patients:

#### Maintaining airway hydration:

Covering the tracheostomy inlet with a transparent moist gauze can offer some humidification but the gauze piece should be repeatedly moistened. Plenty of oral fluids is crucial in maintaining the humidity of airway mucosa. Steam inhalation is helpful. Temperature more than 410 C can damage the airway mucosa, so one should maintain adequate distance between the stoma and hot steam. Sterile saline sprays are available that can be repeatedly sprayed through the stoma to maintain the humidity of the airway

#### Tube care

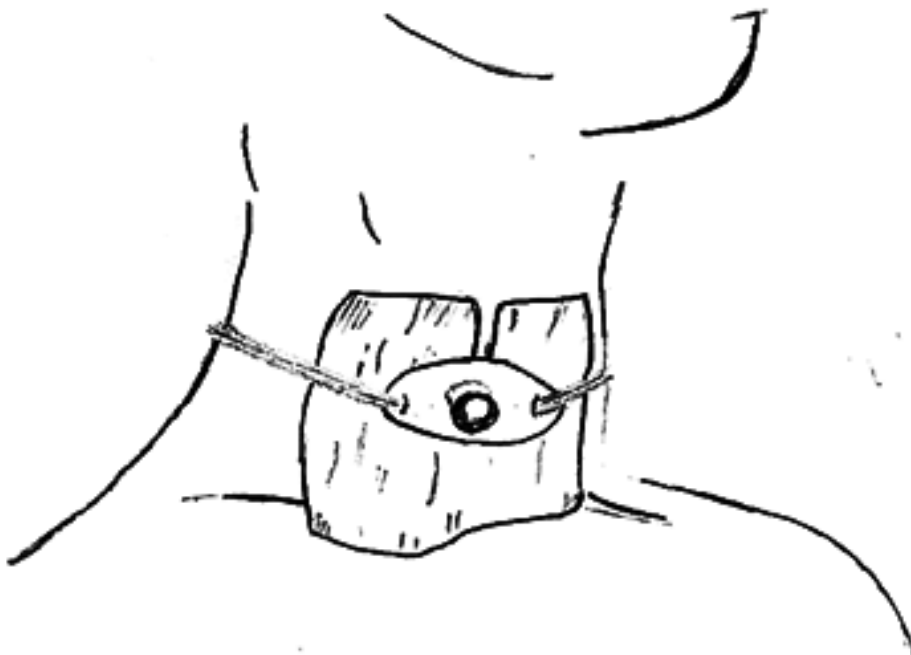
While caring for metal tubes one should remember **never to remove the outer tube**. Only the inner tube should be removed. After removing the inner tube, the tube should be washed with running water. Once the secretions are removed with the running water the inner tube is to be boiled for 20 minutes, cooled down on the surface of a clean towel or pad and reinserted.

## Skincare

Self-care of tracheostomy should be performed in front of the mirror. The peristomal skin should be cleaned with warm saline and a new vaseline gauze should be applied between the neck plate and the skin to prevent injury. It is important to ensure that there is only minimal displacement of the tube while placing a Vaseline gauze between the neck plate and the skin. Early signs of peristomal skin infection are redness, swelling warmth and tenderness. These should be reported and appropriate care should be given.

## Tie changing

Tie or a Velcro strap is used to hold the outer tube in place. Tie changing is better avoided for a few days if the patient has coughing tendencies to prevent accidental decannulation. There should be one fingerbreadth gap between the tie and the neck.



Vaseline gauze placed between the neck plate and the skin

### Tracheostomy suctioning:

Suctioning is recommended only if there are excessive secretions that are causing discomfort to the patient. Suction pressure should be set between 100-120mmHg. Advise the patient to take 2 to 3 deep breaths before starting the suctioning. The suction catheter should be inserted only for about 6 inches or until the point of resistance. No suctioning should be done while inserting the catheter. Suctioning should not be performed for more than 10 seconds. Use rotatory motion while pulling the tube out during the suction process. Clear the suction tube in-between suction with sterile normal saline. Encourage the patient to take several deep breaths following the suction and if oxygen is available hyperoxygenation can be done following suctioning. In the absence of a suction machine, tracheostomy suction can also be performed with a 10mL syringe and an infant feeding tube.

## **Supportive care of bedridden patients**

### **Common problems in a bedridden patient:**

- Pressure sores
- Constipation and faecal incontinence
- Urinary incontinence and urinary tract infection
- Vomiting, aspiration, and nasogastric tube feeding
- Malnutrition
- Contractures and wasting
- Isolation
- Depression

### **Needs of a bedridden patient:**

- Nursing care (oral care, eyecare, skincare, and nail care)
- Nutritional needs
- Psychosocial needs (communication and companionship)

### **Prevention and management of common problems in bedridden patients:**

#### Pressure sore:

(Discussed in the chapter on pressure sore)

### Constipation and faecal incontinence:

Constipation is very common with these patients because of poor mobility and lack of dietary fibres in the presence of nasogastric tube feeding. In patients with nasogastric tube feeding, the carer sometimes resort to giving only clear fluids because of the fear of blocking the nasogastric tube. Thus, the diet provided to the patient severely lacks dietary fibres. Reassuring the carers and encouraging them to provide thoroughly ground vegetables and fruits is important. Active and passive exercises promote gut motility. Many bedridden patients will require laxative support in addition to other non-pharmacological interventions. Imbalanced laxative therapy can lead to diarrhoea and vomiting. In bedridden patients under laxatives, ensuring adherence is often a challenge. This often takes time and repeated reinforcement.

Problems associated with faecal incontinence:

- Peri-anal excoriations
- Secondary skin infections
- Bedsores
- Severe impact on patients sense of wellbeing

Managing faecal incontinence can be very challenging. To effectively manage faecal incontinence the bowel routine must be regularized (preferably with laxatives). Suppositories are more helpful in such situations than oral laxatives as bowel movements followed by placing suppositories can be expected within one to two hours. The use of diapers is discouraged as they can cause rashes, infections, and excoriations.

### Urinary incontinence and urinary tract infection

Urinary incontinence is the inability to store the urine in the bladder and excrete voluntarily where and when it is socially acceptable. It severely impacts dignity and self-esteem and also impacts the patient-caregiver relationship.

Problems due to urinary incontinence:

- Pressure sores
- Skin excoriations
- Secondary fungal and bacterial infection
- Poor sense of well-being
- Caregiver conflicts

### Managing urinary incontinence:

The first step in managing urinary incontinence is to identify the reversible causes of incontinence.

- Constipation
- UTI
- Enlarged prostate
- Poor access to toilet

Whenever possible condom drainage should be preferred over indwelling catheterization. In patients with an indwelling catheter, bowel evacuation should be regular as the distended rectum and impacted stool can occlude the catheter and obstruct the urinary flow resulting in UTI.

### Condom drainage:

Condom catheters are external catheters that are worn around the penis to drain the urine into the collection bag

It is appropriate in the following situations

- Urinary incontinence
- Over reactive bladder
- Dementia
- Mobility related issues

Condom drainage is not useful when there is retention or obstruction

### Advantages of condom drainage:

- Greatly minimizes the risk of UTI
- More comfortable
- Non-invasive
- Costs less
- Easy to learn
- Better mobility and confidence

### Instructions for patients on a condom catheter and their caregivers:

1. Instruct the patient and the family caregiver to buy two condom catheters
2. Condom catheters are available in three sizes – large, medium, and small. Choosing the right size prevents leakage and discomfort.
3. One condom catheter can be applied for 12 hours. It is then washed and dried in the shade while the other condom catheter is used.
4. While applying the condom catheter observe for skin excoriations. If skin excoriations are present the same should be informed to the homecare team.
5. The penis should be cleaned with soap and water while changing the condom catheter. Once cleaned it should be completely dry before the application of the condom catheter.
6. Do not apply any powder or lotion on the penis unless prescribed.
7. Ensure that the tip of the condom catheter or the drainage tube is not kinked. This will obstruct urinary flow and result in urine leakage, skin excoriation, or even urinary tract infection.
8. The drainage tube can be anchored to the thigh to prevent traction
9. The drainage bag should not be placed on the ground. It should always be hung below the waist level.
10. The drainage bag should be tied to the side of the cot rather than at the leg end to prevent traction on the condom catheter.
11. The bag should be emptied when it is more than half full and it should also be emptied before sleeping at night.

Indwelling catheter: It is also called continuous bladder drainage (CBD) where the catheter is retained inside the bladder by inflating a balloon to facilitate continuous drainage. Indwelling catheters are associated with a higher incidence of urinary tract infection. So the use of an indwelling catheter should be the last option.

Indwelling latex Foley's catheters are changed every 3 to 4 weeks according to the manufacturer's guidelines. Silicone catheters can be in place for about 2 to 3 months. The risk of urinary tract infection is more in latex rubber catheters than silicone catheters.

### **Family education for patients on indwelling catheter:**

- Instruct the patient and the family caregiver not to raise the drainage tube or urine bag above the hip level. This is to prevent the backflow of urine into the bladder.
- The patient should consume plenty of oral fluids (2 to 3L per day) unless contraindicated. This reduces the risk of urinary tract infection.
- The bag should be emptied when it is more than half full. This ensures the continuous flow of urine from the bladder.
- Instruct the caregivers to empty the bag before the patient goes to sleep and also in the morning at waking hours. This is to prevent the overfilling of the bag.
- Ensure that the tube is not kinked. A kinked tube obstructs the flow of urine.
- Instruct the carers not to anchor the urine collection bag to the side of the cot and not at the leg end. This is to avoid traction on the tube.
- Instruct the patient and the family caregivers to inform the health care team if the patient has a fever, chills, and lower abdominal pain. These could be the signs of urinary tract infection.
- Instruct the patient and the family caregivers to inform the health care team if they notice urinary sediments, peri-catheter pus discharge, and cloudy urine. These could be the signs of urinary tract infection.

### Urinary tract infection:

Any suspicion of urinary tract infection (UTI) needs to be investigated by multiparameter urine dipstick test if available, urine routine examination, and culture and sensitivity tests to decide the appropriate antibiotic therapy. In bedridden patients, UTI should be prevented as much as possible. Many urinary tract infections are catheter-associated. In a patient who is bedridden indwelling catheterization should be done only when it is absolutely necessary. Whenever possible condom drainage should be preferred over indwelling catheterization. In patients with indwelling catheterization, bowel evacuation should be regular as the distended rectum and impacted stool can occlude the catheter and obstruct the urinary flow resulting in UTI.

### Prevention of UTI in bedridden patients:

1. Plenty of oral fluids, minimum of 2L/day unless contraindicated
2. Prefer condom drainage over indwelling catheters in patients with incontinence
3. Regularize bowel evacuation



### Vomiting and aspiration:

Gastric stasis in bedridden patients can occur due to constipation, poor gastric and intestinal motility, and drugs. The clinical presentation is usually large quantity vomiting, anorexia, and dyspepsia. Interventions that can be helpful are treating underlying causes such as constipation, active and passive exercises. A prokinetic agent such as metoclopramide is very effective.

Since vomiting in bedridden patients can produce life-threatening aspirations the focus of the care should be to prevent them. Constipation in bedridden patients should be prevented at all costs. Giving large bolus feeds should be avoided. Nasogastric feeds can be spaced as 200 to 250mL every two hours. If and when the patient vomits, the patient should be turned to a lateral position immediately. The underlying cause of the vomiting should be identified and treated.

### Nasogastric feeding in bedridden patients:

1. The patient should be propped up to 30 degrees while giving NG feeds
2. 30 degrees elevation should be maintained for about 30 minutes after feeds
3. The daily requirement of 30mL/kg/day is given as 1kcal/mL feeds
4. The feeds can be equally spaced throughout the day as every 2 hours
5. Bolus feeds should never exceed 400mL
6. Nighttime feeds should be avoided.

Weaning the patient from nasogastric feeds can reduce the risk of aspirations but weaning may not be possible in all patients. If weaning is tried, one should always start with sips of clear fluids as they are easily coughed out if aspirated.

### Malnutrition:

The bedridden patient often suffers from malnutrition. Malnutrition in these patients is significantly associated with constipation, vomiting, bedsores, infections, and hospitalization. So, to ensure adequate nutrition these patients should be protected from these health complications. On an average, the nutritional requirement of a bedridden patient without any pressure sore is 1000 Cal/day but in the presence of a pressure sore the requirement increases to 1300 to 1500 Cal/day based on body weight. In bedridden patients with mild to moderate illness the daily protein requirement is 0.8 to 1.2 g/kg/day and this requirement increases to 1.2 to 1.5g/kg/day with a critical illness.

### Muscle wasting and contractures:

Disuse atrophy is a very common presentation in bedridden patients. Sarcopenia characterized by loss of skeletal muscle mass and function severely affects the quality of life. Both contractures and muscle wasting results in joints and pressure points becoming more prominent. They increase the difficulty in positioning the patient resulting in pressure sores. Two important strategies to prevent muscle wasting and contracture are physiotherapy and nutritional support. Range of motion exercise when performed regularly can prevent contractures of joints. Regular physiotherapy other than serving as a protection from sarcopenia can also reduce the risk of constipation and gastric stasis. Many of the chronically ill patients are osteoporotic and the risks of aggressive physiotherapy need to be balanced against the benefits in such patients.

### Psychological wellbeing:

In the face of several physical problems faced by bedridden patients and with the family and the health care team addressing these physical issues, the psychological pain and distress of these bedridden patients is often overlooked. Psychological distress in these patients manifests as sadness, depression, irritability, and anger. Since the prevalence of depression is high among elderly individuals, it is always prudent to evaluate all the bedridden patients for depression in routine clinical practice. Since these patients are confined to one room, without any social interaction they often feel isolated. Breaking this isolation is one of the foremost steps in promoting the psychological well-being of a bedridden patient. A compassionate presence alleviates psychological distress caused by isolation. Bringing the patient out of the home in a wheelchair mitigates the effect of disability and improves social interaction. Communication plays a vital role in protecting the psychological well-being of the patient. Talking to the patient about one's daily routine is a simple way to engage in a conversation with a patient. Such conversations serve as eyes and ears of the patient who is confined to a room. Another important aspect of communicating with these patients is actively listening to them. Active listening does not require any advanced skills but can be done by anyone who has time and attitude.

### **Nursing care in bedridden patients:**

#### Oral care:

A good oral hygiene promotes a sense of well-being. Oral problems in a bedridden patient can affect nutritional status and severely affect the sense of well-being. The frequency of oral care is dependent on the condition of the patient.

- If the patient is bedridden and at low risk of developing oral problems oral care every 4 to 6 hours is sufficient.

- For patients with oral problems, 2 hourly oral care is required.
- Hourly oral care may be required for patients with mouth breathing.

To be remembered while providing oral care:

1. If the patient has painful oral ulcers, consider using analgesics or local anaesthetics before performing oral care.
2. To prevent aspiration oral care must be performed in a lateral position in unconscious patients.
3. If affordable soft bristle brush can be used. If not, bristles of a regular brush can be cut and covered with cotton gauze or cotton cloth can be used instead.
4. The direction of cleaning is from the gum towards the crown. The tongue should be cleaned from inside towards outside (posterior to anterior).

Oral cleansing agents:

The choice of an oral care agent is dependent on the aim of care.

Agents	Advantages	Disadvantages
<b>Clean water</b>	Can provide refreshment Readily available Ideal for rinsing the mouth and moistening	Refreshment is short-lasting No bactericidal action
<b>Normal Saline</b>	Can provide refreshment Can be prepared at home setting	Very little bactericidal action The patient may find the taste unpleasant Can cause dryness
<b>Saline with lime</b>	Can provide refreshment Can be prepared at home setting Stimulates salivary secretion	The patient may find the taste unpleasant
<b>Toothpaste</b>	Can provide refreshment that can last longer Effective in removing plaques and debris	Can cause pain if oral ulcers are present Can cause dryness if not rinsed adequately
<b>Sodium Bicarbonate solution</b>	Raises oral pH inhibiting bacterial growth Loosens debris and thick mucus	Nil

<b>Chlorhexidine Solution</b>	Effective bactericidal action Most effective in removing the plaques and debris	Can cause a severe burning sensation if oral ulcers are present Costly
<b>Metronidazole solution</b>	Has very good antimicrobial action, especially against anaerobes	The solution is extremely bitter

### Bed bath:

When the patient is completely bedridden bed bath is provided to maintain skin hygiene. Though a bed bath is not as effective as showering, it is an ideal alternative when the patient can't be moved to the bathroom. The frequency of bed baths can vary based on the age and general condition of the patient. Older individuals may not tolerate frequent baths, so a bed bath is provided about 2 to 3 times a week. But younger individuals can tolerate more frequent bed bath. If a bed bath is not given daily, the area that is more prone to contamination like the perineum and axillae where there is excessive moisture should be cleaned every day.

### Points to remember while giving a bed bath:

1. Always use warm water while giving a bed bath.
2. While giving a bed bath expose only the area that is being washed.
3. Always start with the face, upper limb, chest and abdomen, lower limb, back, and finally the perineum.
4. Soap should be removed completely to prevent dryness.
5. Change the water if it is dirty or cold.
6. Change the water and the washcloths after washing the perineum.
7. Pat and dry the skin instead of rubbing to reduce friction.
8. Apply emollients after bathing the patient.
9. Maintain constant communication with the patient during the procedure, even if the patient is unconscious.
10. While giving a bed bath, monitor the pressure points for possible skin changes.

### Back care:

Back care can be provided to a bedridden patient daily. When performed regularly, back care promotes circulation, greatly minimizes the risk of developing a pressure sore, and improves the sense of well-being.

Points to remember while giving back care:

1. Back care can be performed in a sitting or lateral position.
2. Use emollients or oil while performing back massage
3. Assess the pressure points for possible skin changes
4. Do not massage over the area with skin changes

Watch the following video for back massage: <https://youtu.be/q8Y3glVLJ9s>

### Eyecare:

Eyecare includes cleaning of eyes and circumorbital region. Unconscious bedridden patients will require frequent eyecare in a day as they are susceptible to eye problems.

Points to remember while caring for the eyes:

1. Boiled home-made saline or readymade sterile saline is used to clean the eye.
2. Readymade gauze or clean cotton cloths available at home can be used for cleaning
3. Always clean the eye first and then the circumorbital region.
4. While cleaning the eye, clean from the inner canthus toward the outer canthus
5. Use separate gauze/cloth for each eye and for each stroke of cleaning.
6. Unconscious patients may require lubricants and eye patches to keep their eyes closed to prevent corneal dryness and ulcers.

### Nail care:

A good nail care in a bedridden patient reduces the risk of infection and injuries both to the patients and carers. It also promotes a sense of well-being.

Points to remember while giving nail care:

1. Soak the fingernails and toenails in warm soap and water for 10 to 15 minutes before cutting.
2. If there is excessive dirt underneath the nails, brush them out gently.
3. While cutting always remember to cut the nails straight across and not into the curved edges. Cutting into the curved edges causes injury which can get infected.

### Care of ears:

1. Ears should be cleaned while providing a bed bath.
2. Clean between the earfolds as dirt gets accumulated there.
3. Examine the external ear canal by pulling the ears upward and backward for the presence of cerumen or discharge.

If there is excessive cerumen consider using cerumenolytics, avoid using cotton swabs as it can cause injuries.

### **Lymphoedema:**

Lymphoedema is defined as accumulation of lymphatic fluid within the interstitial space due to imbalance between production and transportation of interstitial fluid resulting in oedema. It usually presents as swelling of one or more extremities along with the swelling of the corresponding trunk. Lymphoedema can cause severe physical and psychological distress. Though lymphoedema is a chronic, incurable condition, it can be managed effectively and its effects can be alleviated. When ignored, lymphoedema can progress into a large swelling and become difficult to manage resulting in disarticulation.

### **Classification of lymphoedema:**

Based on the aetiology lymphoedema is classified into primary lymphoedema and secondary lymphoedema.

#### Primary lymphoedema:

Primary lymphoedema is due to congenital defect in lymph conduction system. E.g. Milroy's disease

#### Secondary lymphoedema:

It is an acquired lymphoedema. It happens in response to damage to the lymph nodes or lymphatic vessels (E.g. lymph node dissection) or due to functional deficiency (E.g. dependent lymphoedema).

### **Causes of secondary lymphoedema:**

- Surgery (lymph node dissection, scaring)
- Trauma (circumferential wound, burns)
- Malignancy (lymph node infiltration, tumour compression)
- Infection (filariasis, lymphadenitis)
- Venous disease (chronic Venous insufficiency)
- Immobility (dependency oedema)

## **Reducing the risk of developing lymphoedema:**

In reducing the risk of lymphoedema one should understand that the recommendations are based on common sense thinking and physiologic principles. These recommendations are not based on research evidences.

- Maintain optimal body weight
- Keep the nails cut short to avoid injury
- Avoid BP measurement and needle pricks on at risk side
- Avoid tight fitting underwear
- Avoid tight fitting watches or jewellery
- Avoid exposure to extreme cold or heat
- If recommended use compression garments
- Regular exercise and limb elevation
- Periodic circumferential limb measurement in patients who had undergone mastectomy to detect the changes early

## **Early signs of lymphoedema:**

1. Feeling of tightness of cloths, jewellery and sleeves
2. Heaviness, fullness and tightness of affected limb
3. Aching and tiredness
4. Observable swelling or asymmetry with the other limb

## **Clinical features of lymphoedema:**

- Swelling of affected limb (can be both pitting and non-pitting)
- Heaviness, fullness and tightness of affected limb
- Hyperkeratosis
- Papilloma
- Joint stiffness
- Lymphorrhoea
- Positive Stemmer's sign (Inability to pinch and lift the skinfold at the base of second toe or middle finger)

## **Assessment of lymphoedema:**

Assessment for lymphoedema should begin with detailed medical history of the patient. In a palliative care setting lymphoedema is usually associated with malignancy. So, the medical history of a patient with lymphoedema should include status of malignancy, history of treatment which includes surgery, chemotherapy and radiation therapy. Since lymphoedema can occur in patients without any history or treatment related to malignancy other history such as neurological diseases, orthopaedic treatment, vascular problems, immobility and filariasis should be explored. Nutritional assessment is very important as BMI > 25 is a risk factor for lymphoedema.

In assessment specific to lymphoedema onset and duration of the swelling with associated pain and fatigue should be documented. Stemmer sign is usually positive in patients with lymphoedema. Inability to pinch and raise the skin fold at the base of the second toe and middle finger is considered as positive Stemmer sign. Other skin findings observed in patients with lymphoedema are Peau d' orange appearance, hyperkeratosis, lymphorrhoea, lymphangiectasia and papillomatosis.

In addition to physical assessment, a thorough psychosocial assessment is crucial in patients with lymphoedema. Coping with the treatment and adherence to treatment strategies will require a lot of resilience as the treatment of lymphoedema is usually lifelong. Exploring psychological issues and support structures available for the patients will enable in choosing appropriate treatment strategy for the patient and to prevent treatment failure.

## **Limb volume measurement**

Limb volume measurement is vital in determining the severity of lymphoedema and appropriate management plan. It is also the most accurate technique in monitoring the clinical response following management. It should always be performed at the time of diagnosis. While performing limb volume measurement for unilateral swelling both affected and unaffected limbs should be measured. Their difference is expressed in millilitres (mL). More than 10% difference in the volume is considered as oedema being present. It is important to keep in mind that the limb volume of dominant limb is 8 to 9% more than that of the non-dominant limb.

Techniques to measure limb volume:

- Circumferential limb measurement
- Water displacement
- Perometry
- Bioimpedance technique



Water displacement is the most accurate way of measuring limb volume, but due to practical difficulties this technique is not widely used. Perometry uses infrared beam to measure limb volume with very good accuracy, but the cost of the equipment limits its use. Bioimpedance uses electrical current to measure extracellular volume, but this technique is not widely used. Circumferential limb measurement is the most widely used technique in measuring limb volume as it is simple and not expensive. Though this technique is prone for errors, when standard technique is followed the errors can be minimized to a great extent.

#### Principles of measuring circumferential limb volume:

- The person who made the initial measurement should be the person making all the follow-up measurements to reduce interobserver variations
- The ruler should be placed on the flat surface along the limb rather than on the limb to make markings for circumferential measurement.
- Always use inelastic, non-stretch tape to make circumferential measurement.
- Both affected and unaffected limb should be measured

#### Procedure for circumferential limb measurement

##### **Upper limb:**

1. Make the patient sit upright on a chair with the affected limb placed on the table. The palm should face down on the table.
2. With a ruler measure the distance between the nailbed of the little finger to 2 cm above the ulnar styloid and mark this point.
3. From this point mark every 4cm all the way up to 2cm below the axilla by placing the ruler along the ulnar aspect of the limb.
4. With an inelastic tape measure the circumference of the limb at each marked point. Ensure that the limb is relaxed while measuring the circumference.
5. Document these circumferences at each point in patient's assessment chart
6. Repeat the procedure for the other limb

##### **Lower limb:**

1. Make the patient sit or stand comfortably with the foot firmly planted on the floor
2. Measure the distance between the floor to 2cm above the middle part of medial malleolus. Mark this point.

3. From this point, mark every 4 cm all the up to 2cm below the popliteal fossa.
4. If the oedema is present over the knee, make the patient stand or lie down comfortably and continue marking every 4 cm above the knee up to 2 cm below the gluteal crease
5. With an inelastic tape measure the circumference of the limb at each marked point. Ensure that the limb is relaxed while measuring the circumference.
6. Document these circumferences at each point in patient's assessment chart
7. Repeat the procedure for the other limb

The total limb volume can be calculated from these measurements using spreadsheets. But in resource limited settings the circumferential lengths are documented over a period of time and tracked for changes.

### **Management of lymphoedema:**

Treating a patient with lymphoedema usually requires a multidisciplinary team. The management is broadly classified into

1. Skin care
2. Compression garments
3. Massage
4. Exercise

These are called the 4-cornerstone management of lymphoedema. In addition to these, caring for patients' psychosocial needs is crucial in ensuring adherence to the treatment plan and in protecting patient's mental health.

#### Skin care:

Since the patients with lymphoedema are prone to develop several skin problems, they will be required to care for their skin meticulously throughout their life time.

#### **General skin care recommendations:**

- Keep the skin hydrated by applying moisturizers daily
- Avoid soaps that cause dryness
- Protect from insect bites
- Avoid tight fitting cloths and BP recording in the affected arm
- Avoid injections on the affected arm

- Avoid vigorous rubbing while drying
- Regularly monitor the web spaces and clean the area
- Protect from direct heat and sunlight
- Avoid lifting heavy items

### **Common skin conditions in patients with lymphoedema and their management:**

Dry skin: Dryness can range from mild dryness to severe scaly skin. Break in the skin due to dryness can act as port of entry for bacteria causing even cellulitis. Soaps usually cause dryness hence moisturizing soap substitutes are preferred. Dry skin can be managed by applying emollients twice daily especially after washing the area to aid rehydration. Emollients also prevent water loss by forming a protective layer over the skin. Low pH moisturizers can not only rehydrate the skin but also deter microbial colonization.

Hyperkeratosis: Hyperkeratosis occurs due to proliferation of keratin in response to the accumulation of lymphatic fluid. It usually forms brownish or grey patches on the skin. Applying the multilayer bandages reduces the lymph accumulation resulting in reduction of these patches. To prevent dryness emollients are recommended. Emollients containing salicylic acid or lactic acid or dimethicone can aid in desquamation of hyperkeratotic skin.

Folliculitis: In patients with lymphoedema due to compromised local immunity the infection of hair follicle is common. Usually these infections are due to *Staphylococcus aureus*. It can be managed by applying lotions containing chlorhexidine. Folliculitis when not cared well can result in cellulitis.

Cellulitis: Cellulitis can be prevented to a larger extent by meticulous skin care and reducing congestion. Occurrence of cellulitis can complicate other management strategies of lymphoedema as cellulitis and lymphoedema can become a vicious cycle. It is usually caused by Group A Beta haemolytic streptococcus. Cellulitis when occurs it should be identified and treated promptly. The local signs and symptoms include redness, warmth, tenderness, swelling and pain. It can also cause lymphadenitis. In severe cases of cellulitis systemic presentations seen are high fever, chills, vomiting and headache.

#### Management of Cellulitis:

##### General guidance:

1. Antibiotics should be started as soon as possible
2. Analgesics (Paracetamol or NSAIDs) should be started along with antibiotics for pain
3. Increase the intake of oral fluids

4. Bed rest and limb elevation is recommended
5. Discontinue simple lymphatic drainage and manual lymphatic drainage
6. Low pressure multi-layer bandaging can be tried if tolerated
7. Once the inflammation and pain is reduced compression and physical activity can be resumed

#### Antibiotic use:

'This information is based on a Consensus Document produced by medical experts and facilitated by the Lymphoedema Support Network. The document, originally produced in October 2005, is jointly owned by the British Lymphology Society and the Lymphoedema Support Network'

#### **For homecare:**

##### First line:

- Amoxicillin 500mg Q8H with or without Cloxacillin 500mg Q6H (if Staphylococcus infection is suspected) for 14 days minimum to 1 to 2 months
- If allergic to Penicillin : Clindamycin 300mg Q6H for 14 days

##### Second line: (if no response or poor response to first line for 48 hours)

- Clindamycin 300mg Q6H for 14 days minimum to 1 to 2 months

#### **Criteria for in-patient care**

- Septicaemia (hypotension, tachycardia, severe fever, vomiting or confusion) this is an absolute indication of hospital admission.
- Continuing or worsening systemic signs (fever, chills, rigor, headache and vomiting) even after 48 hours of oral antibiotics
- Continuing or worsening local signs (redness, swelling, warmth, tenderness and pain) even after first line and second line of antibiotics

#### Antibiotic prophylaxis for cellulitis:

If a patient suffers from two or more episodes of cellulitis in a year, then antibiotic prophylaxis should be initiated. Phenoxymethylpenicillin 250mg BD (500mg if BMI  $\geq$ 33) and if allergic to Penicillin, Erythromycin 250mg BD should be continued for two years. After a period of one year the dose of the Penicillin should be halved. If cellulitis recurs after completing the prophylaxis, a lifelong prophylaxis is recommended.

If there is history of animal bite Co Amoxiclav 625mg Q6H can be given prophylactically.

**Note: The incidence of cellulitis can be greatly reduced by effectively managing swelling, folliculitis, fungal infection, in-grown nails, insect/animal bites, dermatitis and open ulcers.**

#### Lymphorrhoea:

When the lymphatic fluid leaks through the skin it is called lymphorrhoea. It happens due to reasons such as excessive accumulation of lymph, abrasions or cuts in the skin (including surgical complications) and worsening congestive heart failure. Lymphorrhoea can cause skin breakdown, abrasions and can be psychologically distressing for the patient. Treatment include limb elevation, sterile absorptive dressing at the site of leakage and pressure bandaging to relieve congestion. Changing the dressing and bandaging will depend on the strike through rate of the leakage. There are anecdotal evidences that somatostatin analogue such as octreotide and lanreotide reduce lymphorrhoea.

#### Lymphangiectasia:

The dilations of lymphatic vessels resulting in small, soft, fluid filled raised projections is called lymphangiectasia. They should be treated promptly and protected as they can rupture and cause lymphorrhoea. This can be managed by bandaging and reducing the swelling.

#### Papillomatosis:

The dilatation of lymphatic vessels resulting in raised projections with associated fibrosis produces papillomatosis. Unlike lymphangiectasia that are soft, the raised projections produced by papillomatosis is firm due to fibrosis. There may also be associated hyperkeratosis. But papillomatosis can be treated with compression bandaging.

#### Fungal infection:

Fungal infection more commonly occurs at the skin folds, between the toes and web spaces. They can occur when there is excessive moisture (sweat) between the skin fold. They usually appear as whitish patches that are itchy. Presence of fungal infection can facilitate secondary bacterial infection. Fungal infection can be treated with Terbinafine 1% anti-fungal cream for two to six weeks. Other barrier ointment such as zinc oxide can be used to prevent skin to skin contact at the skin folds to control moisture. Good nail care reduces the port of entry for both bacterial and fungal infection.

## **Compression:**

Compression has remained the main stay in the treatment of lymphoedema for several decades. Compression is provided either by the use of compression garments (CG) or compression bandaging (CB). Choosing compression garments or bandaging will depend on the nature and severity of the oedema and the ability of the patient to cope with the treatment.

### **Compression garment (CG):**

Hosiery is widely used in India. Duration of the usage of hosiery should be individualized. In some patients it is required during waking hours but other need to wear it only while performing exercise however in some patient groups it needs to be worn 24 hours. Similar to the duration the compression produced by the hosiery should also be individualized based on the severity of the swelling and the ability of the patient to tolerate the treatment.

#### Factors to be considered before using compression garments:

- **Self-care ability:** Presence of arthritis, obesity and heart failure can make to application of hosiery difficult for the patient. They may require assistance or assistive devices to use hosiery.
- **Skin conditions:** Skin conditions such as lymphorrhoea, cellulitis can temporarily affect usage of compression bandage. In patients with cellulitis low pressure multilayer bandaging can be tried as tolerated. But prolonged period without compression should be avoided.
- **Presence of shape distortion:** Readymade compression garments are most ideal for cylindrical limbs. When there is shape distortion patients will require custom made compression garments or multilayer bandaging.
- **Co-morbid conditions and coping:** Presence of vascular disease with impaired peripheral circulation, acute cardiac failure, severe peripheral neuropathy and inability of the patient to tolerate therapeutic level of compression are important factors contraindicating the use of compression garments.

#### Upper limb compression garments:

##### Low compression (14 to 18mmHg):

- Can be used for prophylaxis
- Appropriate for mild lymphoedema ISL Stage 1 and 2
- There should not be any shape distortion

- Can be used for maintenance following compression bandaging
- Can be used for palliation purposes

Medium compression 20 to 25 mmHg:

- Appropriate for moderate lymphoedema
- Used in ISL late stage 2 and 3
- Appropriate for minimal shape distortion

High compression 25 to 30 mmHg:

- Used in severe lymphoedema
- ISL stage 3
- Appropriate for major shape distortion
- Consider switching compression bandaging

**Lower limb compression garments:**

Low compression 14-21mmHg:

- For prophylaxis purposes in subclinical lymphoedema
- Mild lymphoedema (ISL stage 0-2)
- For nil to very minimal shape distortion
- Used in stable cardiac disease, arthritis patients and in neurological deficit
- For maintenance following compression bandage therapy

Medium compression (23 to 32mmHg):

- For moderate lymphoedema
- ISL Stage 2 to 3
- Minimal shape distortion
- Lipoedema
- Phlebolympoedema and with healed ulcer
- Maintenance following compression bandage therapy

### High compression (34 to 46mmHg):

- For severe lymphoedema
- ISL Stage 3
- Well established shape distortion
- Phlebolymphoedema with active ulcer
- Gross forefoot oedema
- Retromalleolar swelling

### Very high compression (49 to 70mmHg):

- Severe complex lymphoedema
- ISL Stage 3
- Major shape distortion
- Pressure resistant lymphoedema (Unable to contain swelling with mild and moderate compression)

### **General guidelines for using compression garments:**

1. Layering for compression garments can be done i.e. by wearing one compression garment over another. Doing this increases the compression by 70%. This helps in managing acute exacerbation and when the patient is not able to tolerate single high compression garment.
2. Taking accurate circumferential measurements is important in getting compression garments that fit perfectly.
3. Measurement for compression garment should be done when the swelling is less i.e. immediately after removing bandage when the pitting oedema is less and special attention should be given at the areas of shape distortion
4. Oil based emollients can damage the integrity of the cloth. One should ensure that the emollients are absorbed into the skin and the area is dry before the application of compression garments.
5. Compression garments may require change every 3 to 6 months or when the elasticity is lost which diminishes the compression pressure.
6. Compression garments should not be worn with the top edges folded down as it creates tourniquet effect resulting in swelling in the areas distal to the fold.



7. Garments will require frequent washing; this should be done according to manufacturer's guidelines.
8. It will be prudent to wear glove or gauntlet while wearing arm sleeve, especially while performing physical activity to prevent hand swelling.
9. To prevent damage to the integrity of the compression garment, a glove can be worn on the other hand while wearing the compression garment.
10. For lower limb lymphoedema, patients with ABPI less than 0.5 should not receive compression garments and will need referral to a vascular specialist.

### **Compression bandaging (CB):**

Compression bandaging has remained invaluable asset in the intensive management of lymphoedema and in managing its skin complications. In compression bandaging, Multi-Layer Lymphoedema Bandaging (MLLB) has proven to be much more effective in reducing the swelling. In MLLB both elastic and inelastic bandages are used. They have their own advantages.

<b>Inelastic bandages</b>	<b>Elastic bandages</b>
<ul style="list-style-type: none"> <li>• Produce high working pressure during the physical activity but the resting pressure decreases as the oedema decreases.</li> </ul>	<ul style="list-style-type: none"> <li>• Though working pressure increases but it is lower than the working pressure produced by inelastic bandage.</li> </ul>
<ul style="list-style-type: none"> <li>• When the muscles contract they compress the interstitial space against the inelastic bandage producing massage effect. This facilitates good pumping action and pushes the lymphatic fluid through the channels.</li> </ul>	<ul style="list-style-type: none"> <li>• Elastic bandages can also retain the compression pressure better when the swelling goes down thereby not necessitating reapplication.</li> </ul>
<ul style="list-style-type: none"> <li>• Inelastic bandages are most ideal for patients who can perform physical activity or they should be passively exercised.</li> </ul>	<ul style="list-style-type: none"> <li>• Elastic bandages suitable for patients who cannot perform physical activity since the elasticity of the bandage maintains constant compression.</li> </ul>

### Indications for using MLLB:

- More than mild lymphoedema (i.e.) >20% difference in the limb volume.
- Severe shape distortion
- Deep skin folds
- Swelling that cannot be contained by compression garment
- Management of skin problems such as lymphangiectasia, papillomatosis and lymphorrhoea

### Contraindications for using MLLB:

- Severe arterial insufficiency (ABPI <0.5)
- Uncontrolled heart failure
- Severe peripheral neuropathy
- Acute deep vein thrombosis

Presence of cellulitis is not an absolute contraindication for wearing compression bandages but can be used with caution and lower pressure. In controlled congestive heart failure bandaging should be applied one limb at a time with caution. Similarly, caution should be exercised in patients with diabetes, sensory deficit and paralysis.

### Articles required for bandaging: (Used in Institute of Palliative Medicine, Kozhikode)

1. Cotton tubular bandage
2. Gamjee cotton roll
3. Inelastic bandage if not available Crepe bandage (4cm, 6cm, 8cm, 10cm, 12cm)
4. Adhesive tape

### **General guideline in the application of MLLB:**

1. Soft tubular bandage and cotton roll is applied to reshape the limb
2. The bandaging should always start distally and move proximally
3. While bandaging, use the entire hand to guide the bandage as close to the limb as possible to prevent creasing and to get good fit
4. Additional padding may be required at popliteal fossa and at elbows

5. If elastic bandages are used, they should be used at 50% extension and 50% overlap
6. If inelastic bandages are used, they should be used at full extension except when they are used on toes and fingers
7. While using inelastic bandage, several layers may be required to get desired pressure.
8. Bandage the limb at slightly flexed position and use figure of eight technique at the joint to minimise creasing at the joints.
9. Bandage should be extended beyond the region of swelling to prevent the swelling proximal to bandage to fluid displacement. It is always ideal to include knee and elbow to prevent this fluid displacement.
10. Figure of eight is more ideal than spiral bandaging as figure of eight has more winding increasing sub-bandage pressure and also the chances of slippage is less.
11. Assess the range of motion, sensation, circulation, fit and patient comfort after application of bandage
12. Involve the patient and the caregiver in the application of bandage and train them in application.

### **Lymphatic massage:**

Lymphatic massage is a process that utilizes gentle, repetitive massage to stimulate normal lymphatic pathways to facilitate lymphatic flow from the congested areas. Lymphatic massage techniques prove invaluable when there is oedema of head, neck and trunk where the application of compression garment is difficult. However, in the treatment of lymphoedema especially the ones in the extremities, to sustain the effects of lymphatic massage compression garments should be used. Lymphatic massage is classified into the following types. While performing lymphatic massage one should avoid vigorous and deep massage. Vigorous and deep massage can cause tissue damage, increase capillary refill and increase the oedema. Lymphatic massage has a greater psychological benefit especially in those with advanced disease that is irreversible. Human touch in a gentle massage communicates to the patient that they matter no matter their condition is and offers greater comfort to the patient even if the therapeutic outcome is minimal to negligible.

1. Manual lymphatic drainage
2. Simple lymphatic drainage

### Contraindications of lymphatic massage:

- Presence of acute cellulitis
- Acute congestive heart failure
- Liver cirrhosis with ascites
- Renal failure
- Unstable hypertension
- Superior Vena Cava obstruction
- On the site of tumours

### **Manual lymphatic drainage (MLD):**

Manual lymphatic massage is always performed by a trained person. When massage is performed regularly the patency of the lymphatic channels can be maintained. But there is no consensus on the optimal frequency of the massage. It is usually performed for up to one hour every day.

### General guidelines for MLD:

1. Manual lymphatic drainage should be started with diaphragmatic breathing and end with diaphragmatic breathing.
2. Should be performed with the patient in supine position unless the swelling is in head or neck in which case the massage should be performed in sitting position
3. The massage is performed by stretching the skin with gentle pressure in one particular direction, by slow repetitive movement with period of rest, allowing the skin to return to its normal position. This is done to facilitate the flow without increasing capillary filtration.
4. Unaffected side should be gently massaged and the lymphatic channels in the unaffected side should be opened first to collect and drain the lymph flow from the affected side.
5. The massage is started proximally first slowly moving distally and the direction of the flow should be towards the heart.

### **Simple lymphatic drainage (SLD):**

In simple lymphatic drainage the patient self-administers the techniques of MLD to direct the lymph flow. It can also be performed by the carer. When performed regularly, SLD

can offer good symptomatic relief, but ensuring compliance is often challenging. The compliance of the SLD depends on the training provided to the patient, self-motivation of the patient and patient's dexterity. Patients who had regular MLD will be able to learn and perform SLD better.

#### General guidelines of SLD:

In addition to the above-mentioned guidelines of MLD, more time should be spent for training the patient in performing SLD.

1. 10 to 20 minutes can be allocated to perform SLD each day
2. Demonstration and written instruction will be helpful to the patient.
3. Competency of the patient/carer to perform SLD and their ability to cope with the treatment should be checked periodically during homecare visits.

#### **Exercise:**

Like the blood which is circulated throughout the body by the pumping action of the heart, the lymphatic channels require the pumping action of the muscles to facilitate lymph flow. Evidences suggest that, exercise increases the interstitial pressure and facilitates lymph propulsion and clearance. Exercise not only facilitate lymph flow but also maintain muscle strength, improve cardiovascular function, improve psychological well-being and improve functional capacity.

#### General guidelines on lymphoedema exercise:

1. Exercise can be performed while wearing compression garments or compression bandages to increase the interstitial pressure.
2. Always start with low intensity exercise and slowly increase the intensity
3. There should be warming up before the exercise and cooling down time with in the exercise to prevent exacerbation of swelling.
4. Deep breathing exercise and aerobic exercise results in pumping of thoracic duct by increasing intra-abdominal pressure
5. A combination of flexibility exercise, aerobic exercise and resistance exercise can be adopted
6. Walking, swimming and cycling are recommended
7. If the patient is paralysed passive exercise can be performed.

### **Subcutaneous (SC) injections:**

Subcutaneous injection is the administration of medication into the subcutaneous fat to be absorbed into the systemic circulation.

### **Subcutaneous infusions or hypodermoclysis:**

It is administration of isotonic solution into the subcutaneous tissue to be absorbed into the systemic circulation. When administered appropriately the absorption of the isotonic solution via the subcutaneous route is in par with the intravenous (IV) administration.

### **Subcutaneous catheters:**

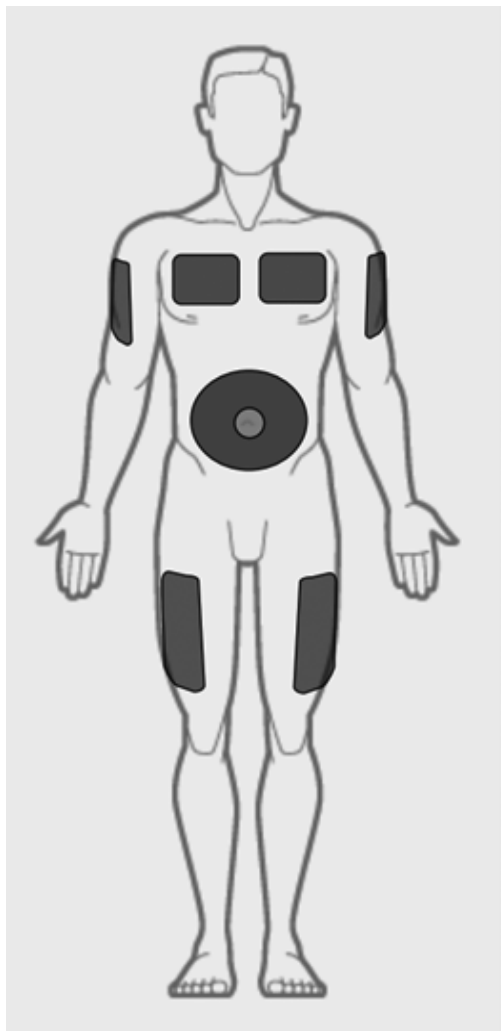
Subcutaneous catheters are devices that are secured at the insertion site to facilitate intermittent subcutaneous injections or infusions. Commonly used subcutaneous catheters are 23G scalp vein set and 26G IV cannula. Both these devices can be placed in the subcutaneous layer and secured for repeated injections or infusions.

### **Pros and cons of subcutaneous infusions and intravenous infusions**

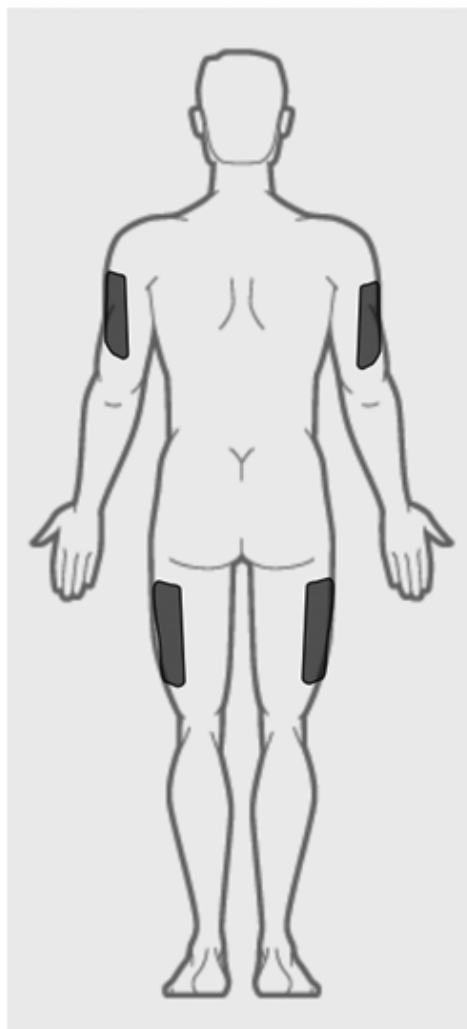
<b>Intravenous administration</b>	<b>Subcutaneous administration</b>
1. Skill is required to initiate intravenous access	1. Minimal skill is required in establishing subcutaneous access
2. Establishing IV access is difficult in patients with advanced disease as the peripheral veins are not very prominent.	2. Establishing subcutaneous access is easy even in patients with advanced disease.
3. Costly	3. Not as expensive as IV.
4. Ideal for emergency situations where rapid volume expansion is required.	4. Infusions should be administered at the rate of 1mL/minute so it is not the ideal route in emergencies where rapid volume expansion is required.
5. When established in a home care setup, IV catheters will require frequent monitoring and supervision.	5. Does not require frequent monitoring and supervision as compared to IV catheters and can be easily managed in homecare setup.
6. Shorter duration of access. Some guidelines recommend only 72-96 hours.	6. Long duration of access. Subcutaneous catheters can be in place for about 14 days.
7. IV administration is most suitable for hypertonic solutions and drugs that can cause tissue irritation and inflammation.	7. Hypertonic solutions and drugs that cause tissue irritation and inflammation cannot be administered via SC route

How to select an appropriate site for subcutaneous infusion:

- The site should have good depth of subcutaneous fat
- The sites that are easily accessed such as the chest and abdomen are more ideal
- Avoid bony prominence and sites close to the joints
- Rotate the sites on a regular basis
- A subcutaneous needle can be in place for a maximum period of 14 day



**A. Anterior view**



**B. Posterior view**

Sites for subcutaneous infusion

Contraindications for subcutaneous infusion:

- Sites with lymphedema
- Sites with pitting edema
- Severe bleeding disorder
- Sites with broken skin
- Sites with recent radiation
- Skinfold

Drugs to be avoided in subcutaneous injections:

1. Promethazine
2. Chlorpromazine
3. Potassium chloride
4. Calcium gluconate
5. Phenytoin

Infusion volume and rate

- The infusion rate should be 1mL/minute for 24-hour infusion
- Maximum of 1500mL can be administered over 24 hours at one site. A total of 3000mL can be administered over 24 hours as 1500mL in two different sites.
- For bolus infusion, 500mL/2 hours three times a day can be given
- If a 24-hour infusion is not possible 1000mL / 8 hours can be given
- If medications are given via subcutaneous catheter, no more than 2mL should be given at a time followed by 0.5mL of normal saline to flush
- If more than 2mL needs to be administered, use multiple sites.
- If more than one medication is to be given, wait for 20 to 30 minutes before the administration of the second medication

To watch out for:

Side effects and adverse events following subcutaneous therapy are rare. Following are the signs to watch out for

- Redness
- Swelling



- Tenderness
- Pain
- Warmth

If any of these signs/symptoms are there change the infusion site immediately.

**Instructions for family caregivers following subcutaneous needle placement:**

1. Lumping under the skin is normal after the administration of subcutaneous injections. These lumps will disappear within minutes to hours.
2. Swelling after the subcutaneous infusion is normal. This swelling will resolve on its own within a few hours.
3. Drugs that are refrigerated should be warmed to room temperature before administration.
4. Before the administration of subcutaneous injection through the subcutaneous catheter check the area for redness, warmth, swelling and tenderness. If the area is red or warm or swollen or tender do not administer the drug and call the homecare nurse immediately.
5. If the subcutaneous catheter site is covered by a waterproof dressing patient can be given a bath, but care should be taken not to manipulate the catheter too much.
6. If waterproof dressing is not available, protect the area with absorbent pads and waterproof plastic bags while giving bath to the patient. A bed bath is preferred in these situations.

# Module 7 : Organisation of palliative care

## Steps for setting up palliative care services in hospitals

1. Needs assessment that considers the needs and services for palliative care within the geographical population covered by the hospital should be done.
2. Identify the initial target population for the hospital-based palliative care service. Be realistic in terms of the resources available.
3. Ensure the availability of the essential medicines for palliative care including oral morphine
4. Plan the physical location of the service. Bear in mind that patients who need palliative care may not be mobile and may need more than one caregiver to look after them. All facilities need to be easily accessible to trolleys and wheelchairs. There must also be space for family members to be present with the patient.
5. Plan staffing

	Basic	Mid-level	Advanced
Doctors	Foundation courses (3-10 days)	Residential course (6 weeks)	Fellowship/postgraduate qualification in palliative care (1-3 years)
Nurses	Foundation courses (3-10 days)	Residential course (6 weeks)	Certificate course (4 months), fellowship (1 year)
Community health workers	3-6 hours to supplement prior training	Basic course (3 months/400 hours)	Advanced communication skills/lymphedema management
Volunteers	Introductory course (3 hours)	16 hours theory +4 clinical sessions	Advanced communication skills and train-the-trainer course

Source: WHO 2016. Planning and implementing palliative care services: a guide for programme managers, accessed from

<http://apps.who.int/iris/bitstream/10665/250584/1/9789241565417-eng.pdf?ua=1>

Minimum manpower required to initiate a part time out patient palliative care service with a 4-6 in-patient beds in existing wards

- Doctor: One full time and one part time: The doctor should be a graduate in Modern Medicine with six week hands on training.
- Nurses: A minimum of three nurses with formal training in palliative care (six week hands on training) + six additional nursing hands
- Social Worker: One
- Part time Pharmacist: 10% of the dedicated time of a pharmacist should be earmarked for palliative care related work.

### **Estimates of amount of oral morphine needed**

Based on the expected number of **cancer patients** to be registered with the service.

- Based on the average daily dose for control of cancer pain, being 100 mg/day/patient, and being given for an average time of 100 days. 10 grams per patient per 100 days will be needed. Based on this 1 kg of morphine would cover 100 patients.
- However depending on types of cancers, stage of disease seen and treatment times the total amount needed may vary. The storage time of morphine is 2 years, but biologically usually much longer. It is better to overestimate the opioid needs.

### **Establishing palliative care at the primary health care level**

1. The capacity to address suffering and improve the quality of life of patients with advanced illness depends on the quantity and quality of the manpower involved. The number of health care professionals and non professionals involved and the adequacy of their training need to be looked into.
2. People who can involve in palliative care at the primary health care level are
  - a. Doctors
  - b. Nurses
  - c. Social workers / psychologists
  - d. Physiotherapists
  - e. Pharmacists
  - f. Community health workers (CHWs) and volunteers
  - g. Family caregivers

3. The core clinical competencies for management of patients with advanced diseases at the Primary Health Care level include
  - a. Identification of suffering/ distress due to incurable illness & recognition of factors behind it
  - b. Offering emotional support to patients and families (Knowing dos and don'ts while talking to patients and families)
  - c. Basic management of key symptoms in advanced diseases
    - i. Pain
    - ii. Breathlessness
    - iii. Nausea/ vomiting
    - iv. Pressure sores
    - v. Fungating wounds
    - vi. Management of various stoma
  - d. Identification and management of terminal symptoms
  - e. Knowing when to refer a patient to a specialist based on the symptoms
4. Many of these are part of the Primary Health Care team's competencies but may require fine tuning.

### **Establishing a palliative home care programme:**

Home-based palliative care provides care to patients in the home in which he/ she lives. It is best delivered by a multidisciplinary team trained in palliative care, including doctors, nurses, physiotherapists, community health workers and volunteers. Fundamental issues around home care include what is provided, to what groups of patients and how it is best funded.

#### **Advantages of home care program**

1. Home care is delivered at home. When people are not feeling well, most want to be at home. Home care keeps families together, which is particularly important in times of illness.
2. Home care prevents or postpones institutionalization.
3. Home care allows maximum freedom for the individual, in contrast to institutions, which are regulated environments.

4. Home care is more personalized – tailored to the specific needs of each individual.
5. Many patients feel more comfortable in their home than in a health-care setting. A home-based service also means that family members are integrated into the process. A home-based approach provides advice and support to family members to help them as caregivers.
6. The home care team can facilitate referral to additional services.
7. Home- based Care can also help to increase community awareness of palliative care. Local resources and support networks can be mobilized, and training can be provided by community health workers to volunteers in the local area.
8. The team that delivers the care at home or at the place where the patient is living must have received proper training in palliative care. It should be both capable and willing to assist the patient and family. Competence and compassion must go hand in hand.

### **Disadvantages of home care program**

Possible disadvantages for the team include clinical care in unfamiliar circumstances, supporting staff not being present on site and time lost in travel resulting in fewer number of patient visits.

### **Essential components of a palliative home care service include:**

- a. A willing patient: The patient should be happy to be looked after at home or in his/her live-in environment by the team. The initial steps in establishing a home care unit include deciding the definition of eligibility criteria for home care services, the early detection of eligible people, and proper needs assessment
- b. A conducive home/live-in environment: If there is the threat of personal harm to members of the team in the home/live-in environment, it will be difficult for them to function effectively.
- c. A properly trained team: The team must have the requisite qualifications and should have received appropriate training in home based palliative care
  - i. Nurses represent the largest group of professional home care employees. Nurses evaluate people who receive home care, develop care plans, provide skilled nursing care and determine whether other services are required.

- d. 24-hour support: Patients and their caregivers should be able to contact the home care team outside their regular visiting hours. Provision for 24-hour support, including emergency support will be very reassuring to the patient and family
- e. Means of transport: The team must have a means of transport which is safe and reliable. The mode of this conveyance may take any form depending on the local circumstances and area to be covered.
- f. Network for supportive care: Links with other agencies and hospitals should be built up by the home care teams so that they can refer patients for supportive care when the need arises. Patients when facing an acute crisis that cannot be handled at home may need temporary admission in a hospice or a local hospital.
- g. Home care kit: Availability of essential medicines and equipment must be assured to the team. They should carry a bag with a properly maintained medical kit on visits
- h. Documents: Patients' medical records must be securely kept even while travelling and properly filed and maintained. Details of interventions to be recorded meticulously

## **Community participation in palliative care**

1. Community support in palliative care may come in many forms: serving food to a starving family, spending time with a lonely patient, mobilizing support for the patient and family from the community, fund raising for the palliative care program, offering emotional support to the patient and family etc.
2. Community volunteer manpower is mainly of two types:
  - a. The untrained volunteer
  - b. The trained volunteer.
3. Untrained sensitized volunteers can provide the groundwork for the palliative care service by establishing a social support system eg; food for patients, transport, educational support for children and by working with the local government. Such volunteers can be motivated and mobilized by sensitization programs in the community

4. Trained volunteers, are those with proper training and can be involved in patient care in a bigger way by offering
  - a. Emotional support to patients and families
  - b. Helping the family /health care worker with basic nursing chores
  - c. Help the patient with mobility (shifting and moving)
  - d. Ensuring adherence to clinical instructions

## Module 8: The last 48 hours of life

### Physical problems seen in a dying person

- Common symptoms at the end of life include
  - a. Noisy-moist breathing
  - b. Urinary symptoms
  - c. Pain
  - d. Restlessness
  - e. Dyspnoea
  - f. Nausea and vomiting
  - g. Profound weakness
  - h. Muscle twitching (myoclonus)
  - i. Confusion (Delirium)

Most of these symptoms can be settled with simple medication.

- Route of administration of drugs need to be changed when the patient cannot take medicines by mouth. Possible options at the Primary Health Care level are :
- Sub lingual

Many drugs used to control terminal symptoms gets absorbed through intact mucosa and so can be administered buccally/ sublingually
- Subcutaneous

A scalp vein (butterfly) needle placed subcutaneously over the arm/ chest wall/ abdominal wall and secured with a piece of transparent dressing can be used to deliver injections (ideally in volumes less than 2ml) easily and painlessly. Most of the medicines usually given intravenously can be administered subcutaneously also. The needle can be kept in the same position for more than a week. The site needs to be inspected every day for any signs of inflammation. Change site if redness is seen at the injection site.
- Rectal

Most of the medicines usually administered by mouth can also be administered per rectally



- **Management of noisy- moist breathing (death rattle)**

Death Rattle refers to noise observed in patients who are too weak to expectorate or are moribund. It is produced in upper airways by secretions (either saliva or the bronchial secretions) during the respiratory cycle. It does not cause hypoxia.

- Non-pharmacologic measures include semi-prone position, withdrawal of parenteral hydration, gentle nasopharyngeal or tracheal suction. Reassurance to family about process is important.

- Pharmacological management:

Atropine 1mg or Glycopyrrolate 0.2mg subcutaneously/ sublingually. Can be repeated 3-4 times a day. Start drugs early because they do not affect existing respiratory secretions.

Hyoscine Hydrobromide 0.4mg or Hyoscine Butylbromide 20mg are also helpful subcutaneously.

Noisy tachypnoea in moribund patients respond well to Injection Morphine 1.5 – 3mg +/- Midazolam 2-3mg subcutaneously

- **Urinary symptoms**

Retention of urine and overflow incontinence secondary to it are common in dying patients not on catheter.

Inattention, drugs with anti-cholinergic properties, weakness and hypertrophied Prostate (in men) are the common causes.

- **Pain**

Pain in an unconscious/ semi-conscious patient presents as restlessness. It is important to continue the analgesics even when the patient is unconscious. Doses of opioids can be reduced to half or one third of the original dose. Usual practice is to resort to subcutaneous route.

- **Restlessness**

Restlessness in an unconscious/ semiconscious dying person can be due to a variety of causes. The common reasons are

- i. Pain
- ii. Pruritis
- iii. Full Bowel/ Full bladder
- iv. Anoxia/ dyspnoea

- v. Anxiety/akathesia/delirium
- vi. Dehydration
- vii. Addition or withdrawal of benzodiazepines/steroids
- viii. Withdrawal of alcohol/nicotine
- ix. Drugs reducing seizure threshold (Phenothiazines/ Butrephenones/ Tricyclic Antidepressants/Opioids)

Detailed history and careful physical examination is needed to rule out these.

- **Management of restlessness**

Treat the cause if identified

- a. unrelieved physical symptoms
- b. delirium
- c. drugs causing restlessness
- d. dehydration

**General symptomatic management:**

- i. If restlessness is not associated with delirium, it can be managed with subcutaneous Midazolam (2-3 mg increments every 30 minutes till the patient settles)
- ii. For restlessness associated with delirium, Haloperidol 3-5 mg/ day subcutaneously need to be added to Midazolam

- **Dyspnoea**

Terminal dyspnoea is most often NOT associated with hypoxia.

Management includes:

- i. Trial of Oxygen
- ii. Titrated doses of Morphine (1.5 mg increments subcutaneously every 20 minutes) supplemented with small doses 2-3 mg every 3-4 hours of subcutaneous Midazolam. The idea is not to knock down the patient, but to achieve a fine balance between settling dyspnoea and deep sleep.

- **Nausea and vomiting**

Appropriate anti-emetics to be given subcutaneously

- **Muscle twitching (Myoclonus)**

Frequent muscle twitching can be a pre-epileptiform phenomenon. Common precipitators/ exacerbators include drugs (introduction /withdrawal – see section on restlessness above), - organ failure, hypoxia, cerebral edema, hyponatremia and hypoglycemia

### Management

- Correct the correctable
- General symptomatic treatment with Benzodiazepines.
  - Midazolam 2-3 mg subcutaneously every 30 minutes , maximum daily dose of 30 mg

- **Confusion (Delirium)**

Treat underlying causes (For example infection)

Review and stop non-essential medications

Check for opioid toxicity

Reduce dose/change opioid

Administer a low dose antipsychotic

Drug of choice is Haloperidol (3mg)

Olanzapine (2.5-5mg) or Quetiapine (25-100mg) can also be used, but do not have any advantage over low dose haloperidol

Benzodiazepines (Diazepam 2-10mg) preferable over anti psychotics in delirium tremens and Parkinson's Disease

## **Additional reading material**

Patients in the last days/hours of life often have unrelieved physical suffering, as well as significant emotional, spiritual, and social distress. Recognizing that a person is entering the imminently dying or terminal phase of their illness is critical for appropriate care planning. Defining when this phase begins is not always straightforward. As a result, suffering may not be properly appreciated, or managed, and medical care may even worsen suffering.

Available data indicates that most people prefer to die at home. Providing a relatively accurate prognosis of life expectancy for patients with an advanced life-threatening illness is difficult. It has been observed that clinicians' prognosis are usually overly optimistic. Nevertheless, it has been shown that the accuracy of clinical predictions of life expectancy is better when the clinical prediction of survival is shorter ( $\leq 3$  weeks).

Though there are various patterns of death trajectory at the end of life, certain signs like sleepiness, diminished consciousness, loss of interest in eating and drinking tend to be present commonly, except in the case of precipitous, unexpected fatal events like massive haemorrhage.

**Reviewing medication:** Many of the drugs that the patient is on (eg; preventative medication) no longer provide therapeutic benefit. Nonessential drugs that are no longer consistent with the overall care plan should be discontinued. Antihypertensives can usually be discontinued, as hypertension is usually not an issue with ongoing weight loss and diminishing fluid intake. Continuation of medications for angina or heart failure need to be based on clinical assessment. Management of patients with diabetes at the end of life need to be individualised. The risks and consequences of hypoglycemia are greater than those of hyperglycemia in patients at the end of life. Anticonvulsants are generally maintained. While stopping the drug it is necessary to taper and stop in the case of cardiovascular medications and those affecting the central nervous system like beta-blockers, clonidine, antidepressants and benzodiazepines.

**Pain and breathlessness:** It has been observed that slightly more than 20 percent of patients dying within 48 hours experience an increase in pain. Short acting opioids (eg; morphine) are the mainstay of treating pain and dyspnea. The aim of anti-dyspneic medication is the suppression of respiratory awareness, not the reduction of ventilatory drive. Long acting opioids like sustained release morphine, fentanyl and methadone may accumulate excessively. For patients not already on morphine, a starting dose of 5 mg of simple morphine orally or 2 mg morphine SC offered every 2-4 hours may be sufficient. Half this dose is recommended for patients with COPD or heart failure, dyspnoeic at end of life or older and frail patients with pain. For patients who have been on opioids for a long time, 10 to 15 percent of the basal daily requirement of opioid, calculated in morphine equivalents, can be offered every two hour.

Use of supplemental oxygen should ideally be restricted to dyspneic patients who are hypoxemic as the routine administration of oxygen to patients who are near death is not supported by clinical evidence. A therapeutic trial of oxygen is may be an option.

**Nausea** — No specific antiemetic has been suggested for patients with terminal illness who have non-chemotherapy and non-radiotherapy-related nausea. National Comprehensive

Cancer Network for treatment-related emesis, suggest an approach that is based upon the clinically determined mechanism of emesis. For patients with gastroparesis, metoclopramide has been suggested as the first choice, steroids can provide benefit for patients with elevated intracranial pressure. For patients with malignant bowel obstruction, steroids, octreotide, and anticholinergics are recommended. Haloperidol 1 mg orally or 0.5 mg SC/IV every six to eight hours as needed can be helpful for treatment of nonspecific nausea at the end of life. The dose needed to be halved for patients over age 65. Addition of a 5-HT<sub>3</sub> antagonist such as ondansetron which may be administered SC could be considered in cases that are refractory to higher haloperidol doses. Dexamethasone may also be helpful because of its non-specific effect on the chemoreceptor-trigger zone.

Dexamethasone 4 to 16 mg/ single dose/ day can actually be an adjunct medication for pain, anorexia, nausea, and asthenia in dying patients.

Delirium: Delirium has multi factorial causes. But it may not always be possible to establish the causes in terminally ill patients before starting treatment. Haloperidol 1 to 2 mg or 1 mg SC/IV with repeat doses every two hours until settled, and then every six to eight hours as needed is the usual management strategy for terminal delirium. For patients with persistent agitated delirium, despite the use of haloperidol, single dose of benzodiazepines in conjunction with haloperidol may work. Olanzapine or chlorpromazine 25 mg IV/IM every six hours may be helpful if sedation is a desired side effect.

Dry mouth/ Thirst: Dry mouth can be a severely distressing symptom which should be prevented with regular mouth hygiene. As long as a patient is conscious, he/she should decide himself/ herself how much fluid to take orally. If, the patient is unconscious, some fluid replacement is advisable as dehydration may lead to delirium, rise in toxic metabolites, etc. About 700 ml over 24 h is the minimum recommended. Fluid replacement may be given s.c. as hypodermoclysis.

Seizures: Seizures may occur occasionally as a new symptom at the end of life. For those who are imminently dying, parenteral benzodiazepines SC/IV can be used to control seizures and to prevent them over the next hours or days. In those patients with a known seizure disorder, continuing the known effective anti-convulsant is the best option as long as the patient is able to swallow medication. If the patient presents with seizures, immediate therapy may consist of diazepam 10 mg rectally or midazolam 10 mg subcutaneously. This can be followed by diazepam 10 mg rectally every hour until the seizures stop, then 20 mg rectally at night; alternatively, midazolam 10 mg s.c. may be given every hour until seizures stop, then 30 mg/24 hr as an infusion.

Terminal airway secretions (Death Rattle): For many patients, troublesome airway secretions occur late in the dying process. The rattling tend to be more distressing to caregivers and family members, though not necessarily for the patients themselves. Glycopyrrolate or atropine have been used to settle secretions. Use of glycopyrrolate is preferred over atropine because of less central effects. The molecular structure of glycopyrrolate, a quaternary compound, impedes entry across the blood brain barrier. Anticholinergics only stop the production of new secretions, therefore, additional measures such as aspiration must be used. A Cochrane review on the other hand, has concluded that there is no evidence that any intervention is superior to placebo for the treatment of death rattle. Discontinuing non-essential IV fluids or enteral feedings combined with positioning the patient on his or her side helps to move the secretions out of the airway.

Noisy tachypnea of respiratory rate of >30/min may be observed in comatose patients, which can give the impression of severe distress. It can be managed by titration of subcutaneous/ intravenous morphine to a rate of respiration of 10–15/min.

# Notes













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