

# Palliative Care Nursing BSc Nursing Semester IV

## Prepared by Pallium India

(Based on the Module outline provided by Indian Nursing Council)



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## Preface

#### Who is the most important person in the palliative care team?

Everyone will agree that the most important person is the care-recipient – that is the patient first and then the family around her/him. But then, in the team delivering palliative care, who comes next as the most important?

My personal answer would be that it is the team member who is able to provide the most valuable service to the patient and family. This could be different in a variety of situations. For the patient rolling in pain, at that moment, it may be the doctor who is able to take away that excruciating symptom. For the person recovering from paraplegia or quadriplegia, it could be the physiotherapist who plays a vital role in enhancing their quality of life. The medical social worker or the counsellor may elicit elements of suffering that others may miss and may be able to do much about them.

Nevertheless, for the majority of patients and families, the most important person could well be the nurse. Whether the person with an illness is at home or an in-patient facility, it would be the nurse who spends the most time with her/him. The nurse provides the most intimate aspects of physical care and gets to know facts and feelings that everybody else may miss. Often, they are also the keepers of ethical practice.

For all these reasons, we rejoiced when the Indian Nursing Council, following decades of advocacy, incorporated palliative care in the curriculum for B.Sc. nursing in 2022. Nevertheless, much too often in our country, there turns out to be a huge gap between policy and implementation. To fill this gap as much as possible, a drafting committee developed at the national level worked hard to create these training modules. The members deserve our gratitude and congratulations.

There is a lot of work to do still. The faculty of around 2000 nursing colleges in the country need to be trained to teach this subject. However, judging by the efficiency of the drafting committee, we can be confident that the activism will continue, and that India will be able to do justice to its millions in needless health-related suffering and their families.

Best regards,

#### Dr MR Rajagopal

Chairman, Pallium India, Director, WHO Collaborating Centre for Training and Policy on Pain Relief, Trivandrum.

#### **Introduction to this Module**

The Indian Nursing Council (INC) update regarding integrating Palliative Care into the UG nursing curriculum from the 2022 batch. According to the latest syllabus, a 20-hours mandatory module on Palliative Care is included in the 4th semester (second year) of the fouryear BSc Nursing Course. INC implies that the module is designed to help students develop indepth knowledge, competencies, and a positive approach to providing quality palliative care to persons suffering from chronic illnesses and resultant health problems in various settings, collaborating with supportive services.

Moreover, palliative care is not only for the patient but also for the family. Therefore, even when the patient dies, psycho-social support may have to be continued for the bereaved family. Thus, nurses play a crucial role in providing palliative care to patients. With this aim, a team of experts from Pallium India prepared these modules as per the syllabus prescribed by the Indian Nursing Council for second-year BSc Nursing students. This module is an introduction to palliative care nursing. This module has been compiled to assist BSc Nursing students and their faculties in supporting the curricular requirement of the BSc Nursing syllabus. Palliative care nursing is an important and rewarding field of nursing, as itallows nurses to make a meaningful difference in the lives of patients and families facing serious illness.

Nurses, Nursing faculty and students can contact Pallium India (<u>https://palliumindia.org/</u>) for information about the courses provided in palliative care nursing, training resources etc. More information about these courses is given in Annexure. For planning a palliative care unit visit the palliative care directory by Pallium India (<u>https://palliumindia.org/clinics</u>) or the Indian Association of Palliative Care (<u>https://www.palliativecare.in/palliative-care-directory-of-india/</u>) can be used. The editors of this module have also included some useful videos for in-depth learning. The users of this module can watch these videos with the links provided in Annexure. We hope you will find this module helpful in learning palliative care nursing.

Wishing you all success,

Dr Sreedevi Warrier

Head, Education and Skill Building Pallium India, Trivandrum

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### ACKNOWLEDGEMENT

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## PALLIATIVE CARE MODULE (Adult Health Nursing II)

(Module outline provided by Indian Nursing Council)

#### PLACEMENT: IV SEMESTER

#### Theory & Practical: 20 hours

Theory: 15 hours

Practical: 5 hours

**Module Overview:** This module is designed to help students to develop in-depth knowledge, competencies, and a positive approach to providing quality palliative care to persons suffering from chronic illnesses and resultant health problems in a variety of settings, collaborating supportive services.

#### Competencies (Learning Outcomes): The student will be able to

- 1. Explain the concept and significance of palliative care.
- 2. Identify the need for palliative care.
- 3. Discuss the importance and techniques of effective communication in palliative care.
- 4. Demonstrate skill in assessment, management and evaluation of pain and common symptoms.
- 5. Provide optimum nursing care to relieve symptoms and promote comfort.
- 6. Demonstrate competency in performing nursing procedures related to palliative care.
- 7. Assist the patient to experience maximum Quality of Life.
- 8. Support patient and family for home care and to cope with the terminal phase of illness.
- 9. Observe ethical and legal principles binding palliative care.

#### LEARNING ACTIVITIES:

- Lectures and demonstration
- Self-study/Reading assignments
- Written assignments
- Practice in Skill/Simulation Lab

#### ASSESSMENT METHODS:

- Test paper (objective type/short answer/situation type) 20 marks
- Assignments 10 marks
- OSCE (Health assessment & Symptom management competencies) 20 marks

Weightage to Internal Assessment: 10 marks to be added to internal marks to make up the total of 40 marks.

## CONTENT OUTLINE

Unit	Time (Hours)	Learning Outcome	Content	Teaching/Learning Activities	Assessment Methods
Ι	2	Explain the concept significance of palliative care. Identify the need for palliative care.	<ul> <li>Palliative Care</li> <li>Evolution, and History</li> <li>Concept of palliative care</li> <li>Significance</li> <li>Components</li> <li>Differences between conventional and palliative care - approaches</li> <li>Ethical aspects</li> <li>Need for palliative care</li> </ul>	• Lecture cum Discussion	<ul><li>MCQ</li><li>Short answers</li></ul>

#### T - THEORY, P - PRACTICAL

Unit	Time (Hours)	Learning Outcome	Content	Teaching / Learning Activities	Assessment Methods
Ш	2	Discuss different aspects of effective communication. Describe how to deal with extremes of emotions.	<ul> <li>Communication Skills</li> <li>Effective communication <ul> <li>needs and barriers</li> </ul> </li> <li>Non-verbal communication</li> <li>Learning to communicate patients with advanced and progressive diseases.</li> <li>Communicating bad news</li> <li>Managing collusion</li> <li>Managing anger and denial</li> </ul>	<ul> <li>Review</li> <li>Discussion</li> <li>Simulation</li> <li>Case Scenario</li> </ul>	<ul><li>MCQ</li><li>Short answers</li><li>Role play</li></ul>

ш	8 (T) 2 (P)	Demonstrate skill in assessment, management and evaluation of pain and other common symptoms. Apply non- pharmacological and pharmacological nursing interventions for pain relief. Render optimum nursing care to relieve symptoms and to promote comfort. Prepare the patient and caregiver for continued care.	<ul> <li>Nursing Management of Symptoms</li> <li>Holistic approach in symptom assessment and management,</li> <li>Pain - concept, assessment, and evaluation of pain, patho- physiology of chronic pain,</li> <li>WHO ladder for pain management</li> <li>Morphine - steps in calculating dose for oral Morphine, management of opioid overdose and side effects,</li> <li>Nursing interventions for management of pain</li> <li>Management of dyspnea, nausea and vomiting, constipation, diarrhea</li> <li>Nutrition and Hydration</li> <li>Fatigue and Powerlessness</li> <li>Anxiety, Social isolation</li> <li>Spiritual distress</li> <li>Impaired physical mobility</li> <li>Self-care deficit</li> <li>Delirium</li> <li>Caregiver role strain</li> </ul>	<ul> <li>Review</li> <li>Discussions</li> <li>Demonstration</li> </ul>	<ul> <li>Case study</li> <li>Written assignment</li> <li>Essay</li> </ul>
IV	1 (T) 3 (P)	Demonstrate competency in performing nursing procedures related to palliative care	<ul> <li>Nursing Procedures</li> <li>Wound care</li> <li>Colostomy care</li> <li>Subcutaneous injection</li> <li>Oral hygiene</li> <li>Naso-gastric tube management</li> <li>Tracheotomy care</li> <li>Assisting in thoracentesis</li> <li>Assisting in indwelling ascitic catheter placement</li> <li>Lymphoedema management</li> <li>Bladder care</li> </ul>	<ul><li> Review and discussions</li><li> Simulation</li></ul>	• OSCE
V	2 (T)	Discuss measures to improve Quality of Life. Explain care in the terminal phase, loss and grieving process.	<ul> <li>Optimization of care</li> <li>Quality of Life</li> <li>Essential care</li> <li>Anticipatory prescription</li> <li>Dying with dignity</li> <li>Care during the terminal phase</li> <li>Ethics based decision making</li> </ul>	<ul> <li>Review and discussion</li> <li>Case scenario</li> <li>Observation visit to a palliative care facility</li> </ul>	<ul> <li>Short answers</li> <li>ObservationVi Report</li> </ul>

Unit	Time (Hours)	Learning Outcome	Content	Teaching/Learning Activities	Assessment Methods
		Observe ethical and legal principles applied to palliative care.	<ul> <li>Death and dying, end of life</li> <li>Support to the caregiver and family</li> </ul>		

#### **References:**

- Rajagopal, MR. (2015). An Indian primer of palliative care for medical students and doctors. Kerala: Trivandrum Institute of Palliative Science publication.
- Palliative care module prepared by WHO CC of Trivandrum and Calicut (Latest version to be used as and when available)

## Unit I PALLIATIVE CARE

#### Introduction

Nurses are often considered the heart of healthcare because they play a vital role in providing compassionate and competent care to patients. They are the frontline healthcare professionals who spend the most time with patients and their families, providing support, education, and advocacy. Nurses provide care to patients in all contexts and stages of their lives. Their contributions are crucial in meeting the needs of palliative care patients and their families.

Let us start with Virginia Henderson's definition of Nursing (1966) - "The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (**or peaceful death**) that he/she would perform unaided if he/she had the necessary strength, will or knowledge". The nurse provides much of the care and support to patients and families throughout a disease trajectory and is more likely to be present at the time of death than any other health professionals. It is a combination of clinical competence and effective communication with fidelity to the patient, the ability to listen and remain present in the face of much suffering and distress.

Despite medical technology and biomedical engineering advances, patients and families with health-related problems suffer needlessly. Palliative care(PC) is an effective model for relieving pain and other symptoms and ensuring the quality of care. Palliative care can be provided from the time of diagnosis and can be given simultaneously with curative treatment. While caring for patients with various diseases, nurses may come across patients needing palliative care and support. Through the units of this module, we shall look at the approach and gain knowledge, skills and a favorable attitude towards providing compassionate and quality palliative care.

#### **Evolution and History of Palliative Care**

The word "Palliate" is derived from the Latin word 'pallium' meaning cloak, i.e., an allencompassing care which "cloaks" or protects the patients from the harshness of the distressful

symptoms of the disease, especially when cure is not possible.

Care of the sick has been a constant concern of human society throughout history. We have ancient traditions in India for special care and attention for those whoare very old, ailing or dying. The eighteen institutions built in India by King Asoka (273 - 232 BC) had characteristics very similar to modern hospices.

Although the hospice movement claims its origins in the 11th Century through the work of the Sovereign Order of St. John of Jerusalem during the Crusades, the modern hospice movement has its roots in the nineteenth Century.

**Dame Cicely Saunders, a** triple-qualified professional as a nurse, social worker and then doctor,



Fig.1.1: DAME CICELY SAUNDERS

founded the first modern hospice - St. Christopher's Hospice, in 1967, in South London. It quickly became a source of inspiration to others. A new view of caring for the dying began to emerge, which helped to refine ideas about the dying process and to explore the extent to which the patients need to know about their terminal condition. Saunders recognised that nurses were central to caring for people at the end of life because of their constant presence and skill in assisting patients in finding opportunities in suffering and peace. Her work provided the foundation for modern hospice care.

#### **Concept of Palliative Care**

#### **Palliative Care**

The World Health Organization defines Palliative care as - "an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illnesses by the prevention and relief of suffering through identification and impeccable assessment and treatment of pain and other problems- physical, psycho-social and spiritual."

Palliative care is thus the total, active care of patients suffering from life-limiting illnesses along with the care of their families." It relieves suffering and improves the quality of both life and death. Palliative care is all about looking after people with illnesses that cannot be cured, relieving their suffering and supporting them through difficult times.

#### Key Concepts in the WHO Palliative Care Approach

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance the quality of life and may also positively influence the course of illness;
- applicable early in the course of illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand better and manage distressing clinical complications.

#### WHO definition of Palliative care for children

Palliative care for children represents a special, albeit closely related, field to adult palliative care. The WHO's definition of palliative care appropriate for children and their families is as follows (the principles apply to other pediatric chronic disorders too):

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multi-disciplinary approach, which includes the family and makes use of available community resources; it can be successfully implemented

even if resources are limited.

• It can be provided in tertiary care facilities, community health centers and even in children's homes.

#### **Scope of Care**

Palliative care aims to improve a person's quality of life when faced with a severe or lifethreatening illness. It can begin during an illness, last days or even years, and be provided with curative treatments.

Palliative care is not restricted to people receiving end-of-life care. It can be offered to anyone whose illness is reducing their quality of life, impacting their ability to function normally, or placing an undue burden on family or caregivers.



Fig.1.2: SCOPE OF PALLIATIVE CARE

The scope of palliative care may involve:

- Reduce or stop the pain, suffering, and other physical symptoms caused by disease and its treatment
- Coordinating care between medical and non-medical providers
- Minimizing side effects from treatments
- Addressing the emotional, spiritual, and social needs of the individual
- Finding and supporting the needs of the family or caregivers
- Cure the condition whenever it is possible
- Help to regain and sustain health
- Early identification and prevention of diseases and complications
- Addressing a person's spiritual needs or concerns
- Addressing a person's practical needs, such as transportation and financial concerns

#### **Standard Terms Used in Palliative Care**

**Life-limiting illnesses**: This term describes illnesses where all activities that make a person feel alive get restricted, e.g., paraplegia. The term may also be used for diseases where death is expected as a direct consequence, e.g., advanced cancer.

**Hospice and Hospice Care:** Hospice care is used when a disease, such as advanced cancer, gets to the point where treatment can no longer cure or control it. Hospice care should generally be used when a person is expected to live about six months or less if the illness runs its usual course. People with advanced cancer should discuss with their family members and the doctor to decide when hospice care should begin.

**Supportive care:** It is all that helps the patient to maximize the benefits of treatment and to live as best as possible with the effects of the disease. This may be nutritional advice, physical therapy, antibiotics, symptom control, transfusions, or counselling. It helps the patients and their families through pre-diagnosis, diagnosis, treatment, cure, death, and bereavement.

**Quality of life:** WHO defines Quality of Life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and with their goals, expectations, standards, and concerns. It is a broad-ranging concept affected complexly by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to their environment."

**Terminal Care:** Palliative care is often misinterpreted as terminal care. However, it refers to the management of patients during their last few days or weeks of life when it becomes clear that the patient is in a progressive state of decline. Another term used is end of life care. Thus, terminal care is a part of the spectrum of palliative care.

**Continuum of care:** It is a concept involving an integrated system of care that guides and supports a patient with chronic illnesses through a comprehensive array of health services. This includes outpatient care (assessment, evaluation, management), patient family education, linking with community-based care facilities (GPs, home-based care programs, link centers) and acute episodic needs and care during advanced stages of the disease (in-patient services).

**Caregivers:** Refers to the relative or friend who cares for the patient or a paid caregiver appointed to take care of the patient.

**Multi-disciplinary care:** Multi-disciplinary care occurs when professionals from various disciplines with different and complementary skills, knowledge, and experience work together to deliver the most appropriate health care. Here, physiotherapists, social workers, psychologists, nutritionists, etc., have significant roles, along with doctors and nurses. This approach aims at the best possible outcome based on a patient's and family's physical and psycho-social needs. As the

needs of the patients change with time, the team's composition may also need requirements to meet. Nurses are the mainstay professional in the palliative care team, providing frontline care.

**Suffering:** It is the distress associated with events that threaten the well-being or wholeness of the person.

**Serious Health-Related Suffering (SHS):** Suffering is health-related when associated with illness or injury of any kind when it cannot be relieved without professional intervention and when it compromises physical, social, spiritual, and emotional functioning.

**Spiritual pain:** Spirituality is that unique dimension in human beings that gives a purpose to their life. It includes searching and finding meaning in life and death, the reason for suffering, and the need for love, acceptance, and forgiveness—faith in God, prayers, religious belief, and their relevance, maybe a path some choose. A person may be spiritual without being religious. Spiritual pain is when these dimensions get disturbed or questioned, leading to suffering. For example, I was kind and fair and did not drink or smoke. Why did this happen to me?"

**Psycho-social pain:** It includes anxiety, fear, apprehension, depression, loss of dignity, loneliness, a sense of being a burden on others, and no longer being valued as a person.

**Dying with dignity:** Refers to the humanitarian concept that a terminally ill patient should have peaceful, natural, and comfortable death rather than being subjected to aggressive, isolating, distressful, costly, and invasive intervention. An example of an undignified death would be a patient with multisystem failure being kept "alive" with long-term mechanical ventilation and regular dialysis in an ICU against his wish.

**Bereavement support:** When a person dies, we say that their family is bereaved. This means they are grieving and have lost someone dear and close to them. The support given to the family to go through this period and return to regular productive life is called bereavement support.

#### **Dimensions of Palliative Care**

Before learning the dimensions of palliative care, let's revise the dimensions of health. The World Health Organization defines health as "a complete physical, mental and social well- being and not merely the absence of disease or infirmity. Health has physical, emotional, social, and spiritual dimensions.

As we discussed earlier, palliative care primarily aims to provide comfort and has a holistic approach, integrating four domains of care: physical, psychological/emotional, social, and spiritual. The domains are intertwined and have an essential impact on each other. Thus, palliative care follows holistic principles, and each person will have a holistic assessment of needs.



#### Fig.1.3: DIMENSIONS OF PALLIATIVE CARE (A)

**Physical Dimension:** The most common physical problems seen among patients are pain, nausea, vomiting, constipation, breathlessness, delirium, nutrition and hydration issues, fatigue, and oral health problems. Common physical issues and their management will be explained in the upcoming chapters.

**Psychological Dimension**: People with progressive, incurable illness may have a depressed mood, fear of metastasis, the unpredictability of the future, anger (Why me?), fear (What will happen to me?), loss (I have lost everything that gave my life value), guilt/blame (I should have gone earlier to the doctor/I did not have the money to see a proper doctor), shame (How will people now treat my family and me?), confusion about what has happened, the future and choices available, family issues, caregiver burnout, grief/despair, loss of hope, fear of separation from loved ones. Moreover, isolation, solitude, helplessness, and despair build up pessimistic feelings in the patient. They also may develop self-hate, low morale and feeling down.

As a nurse, we should explore these concerns. For example, a patient may experience fear, and you need to assess the reasons for his/her apprehension.

The patients may have:

- Fear of isolation
- Fear of loneliness
- Fear of being a burden / helplessness
- Fear of pain or other symptoms
- Fear of leaving unfinished tasks
- Fear of dying

**Social Dimension:** Serious illness can have several social and economic consequences. Some of these are related to the inability to perform social roles. The most common issues are:

- loss (or fear of loss) of job, social position, family role
- feels isolated (actual or perceived)
- feels a burden on family and carers
- Unfinished business: personal, interpersonal
- financial hardship due to higher medical expenses because of prolonged stay in the hospital and staying far from the hospital costs too much for transportation to and fro, having to pay for someone else to look after the children etc.
- Fears for family, including lack of insurance, financial, legal, housing, or job-related issues.

**Spiritual Dimension:** When people become sick and approach the end of their life's journey, there is often a great deal of spiritual suffering. Each person needs to come to terms with their losses in their way. Also, spiritual issues like - "Why has God done this to me? What have I done to deserve this? / Why is God punishing me?" may worry them. Sometimes patients will have-religious issues, bargaining with God, remorse, guilt, unfulfilled expectations, and meaninglessness - a sense of life and suffering has no meaning and regrets with faith can also be a concern. It is essential to understand that spiritual issues are related to the "meaning and purpose of life", and people may ormay not use religious vocabulary to express such needs. Hence spirituality does not necessarily mean religion or faith. It could be that the person needs time to think about their life, have close family with them or for comfort, or have their favorite music playing quietly in their room. Concerns may include who can touch the body, confessional deathbed prayers, funerary practices, and burial clothing. Contact with someone from their faith should be allowed and encouraged if this essential to their personal life and wishes.

#### **Total Pain**

Pain is traditionally perceived as "TOTAL PAIN" with Physical, Social, Psychological and Spiritual dimensions. The term "Total Pain", coined by Dame Cicely Saunders, is used when psychosocial, physical, and spiritual distress combines to affect the patient. All the components should be addressed and treated to relieve 'pain completely'. Relief from total pain improves the quality of life of the diseased and the family. The considerable need for ongoing care for those withlong-term, progressive, or incurable diseases needs to be met within the healthcare delivery system. Thus, exploring a patient's anxiety and frequent misconceptions about these factors can be very beneficial.

The pain will not be adequately controlled unless patients feel a degree of control over their situation. Ignoring such psychological aspects of care may often be the reason for persisting pain. Thus, a holistic approach to treatment is essential in palliative care.



Fig.1.4 DIMENSIONS OF PALLIATIVE CARE (B)

#### **Significance of Palliative Care**

Palliative care is essential because it gives patients options for pain and symptom management and higher quality of life while pursuing curative measures. When a patient is seriously ill, they understand the value of each day. While they face their illness, the support of palliative care in controlling pain and other symptoms can make each day a more positive experience that allows the patient to make the most of their time with their families like:

- Puts the patient's desires, goals, and decisions first.
- Supports the patient and family
- Helps patients and families understand treatment plans.
- Improves quality of life
- Provides pain and symptom control
- Focuses on body, mind, and spirit
- Reduces unnecessary hospital visits
- Receive medical, social, emotional, and spiritual care from people who know what you are going through
- Receive guidance and support in dealing with the healthcare system and individual healthcare needs
- Don't let the symptoms of a chronic illness or the side effects of its treatment stop you from living your life

#### **Components of Palliative Care**

The components of palliative care are those of good clinical practice. Usually, healthcare professionals tend to focus mainly on organs and their diseases. Palliative care recognizes that people are much more than organs; their minds, spirit and emotions are all part of who they are. It also acknowledges the patient's families and communities. So, the problems a sick person and theirfamily face are not just confined to the disease; there may be pain and other symptoms in conjunctionwith psychological, social, and spiritual concerns. Sometimes problems in one area may worsen others, e.g. pain is often worse when people are anxious or depressed. When we address all these areas, we are helping the whole person. It is this holistic approach that distinguishes palliative carefrom conventional medical care.



Fig.1.5: COMPONENTS OF PALLIATIVE CARE

Every care sphere is only adequate considering its relationship with the other two. A holistic approach, incorporating the whole spectrum of care –medical, nursing, psychological, social, cultural, financial, and spiritual– is a good practice of palliative care. This usually necessitates genuine interdisciplinary collaboration and social interventions. They include:

- Safety of the patient and the caregiver
- A caring attitude with the effectiveness of the interventions
- Comfort with both physical and psychological
- Consideration of individuality, including the individualization of the interventions and treatment
- Caregiver's support
- Cultural considerations
- Consent
- Choice of place of care
- Communication

- ٠ Clinical context and appropriate treatment
- Comprehensive inter-professional care ٠
- Continuity of care
- Crisis prevention •
- Care excellence with adequate and updated knowledge and necessary skills
- Fair use of resources

When we address all these areas, we are helping the whole person. It is this holistic approach that distinguishes palliative care from conventional medical care. No single sphere of care is adequate without considering its relationship with the other two-this usually necessitates genuine interdisciplinary collaboration and social interventions.

#### **Palliative Care Team**

holistic The nature of palliativecare is ideally provided by a multi- disciplinary or interdisciplinary team of professionals and other people have received who proper training in he field. Members of this team caninclude but are not to doctors, nurses. restricted psychologists, social workers, counsellors, social workers, dieticians, physiotherapists, spiritual leaders occupational therapists, and music and art therapists. Volunteering is when someone spends unpaid time doing something to benefit others. An important volunteer task in palliative care is to provide emotional and social well support, as as



companionship, which is connected to the idea that the volunteer can become a friend to the patient. Hospitals, home care agencies, cancer treatment centers, and long-term care facilities may offer it.Communication and coordination are critical to the team's success in reducing any stress, fear, exhaustion, and anxiety experienced by the patient and the family.

#### Where can Palliative care be given?

Palliative care can be provided at small Primary Health Centers (PHC), secondary-level hospitals, referral hospitals, and the patient's regular treatment. It should be part of existing health care at all levels of care. Even in far-off areas, low-cost, effective palliative care can be delivered as primary care. Most palliative care is needed in the community and can be provided in villages by training doctors, nurses, community health workers, volunteers, and family members. Some patients with complex symptoms may need to be referred for specialist palliative care.

#### Models of Palliative care provision

The service should ease the patient's stay and care in the home setting whenever possible. The following are ways in which care can be delivered.

- **Out-patient Services:** Addresses the needs of ambulatory patients. In many PC units, as the disease progresses and the patient gets sicker, he continues to access PC services through his caregiver visiting the OPD, thereby reducing the frequency of his visit.
- **Hospital-based palliative care:** Operates with or without dedicated beds in a secondary or tertiary referral hospital. Here patients are admitted for symptom control and occasionally end-of-life care.
- **Stand-alone In-patient palliative care unit Hospice:** What makes a hospice different from a hospital is the holistic, personalised approach and treatment plan, along with the attitude and focused commitment of the staff.
- **Day palliative care unit:** It is a setting for caring for the patients living at home but brought in daily for clinical and social care. These are community-based service centers mostly run by Non- Government Organizations.
- Home-based palliative care services (HBPC): This is based on caring for patients at home. Some patients may be too sick to be travelled to clinics, and some may have economic issues. There is continued need-based care for homebound patients. Home-based palliative care aims to provide comfort and support to the patient and their family and help them manage the physical, emotional, and spiritual challenges that come with aserious illness. Home-based palliative care can be provided by a team of healthcare professionals, including doctors, nurses, social workers, and chaplains, who work together to address each patient's and their family's unique needs by visiting them at their homes periodically. The team may provide services such as pain management, symptom control, emotional and spiritual support, and assistance with daily activities.



Fig.1.7: PALLIATIVE CARE TEAM VISITING PATIENTS AT HIS HOME

Community-based palliative care services (CBPC): Home-based services can become even more effective when the local community takes ownership and actively provides services within their locality. Home care in India is considered better because most patients are more comfortable. It is cheaper and allows the family to care for their loved one without travelling or losing employment. Social support is also more readily available in their native place. Most of the problems are social and beyond the scope of a physician, nurse, or hospital to solve. Thus, most palliative care is required in the community. Community-based palliative care (CBPC) is an emerging field that seeks to integrate palliative and serious illness care with local healthcare systems. The resource centre/palliative care organizations train and coordinates volunteers to provide home-based care for patients with advanced illnesses, including cancer, HIV/AIDS, and neurological disorders. Volunteers may provide practical assistance, such as helping with bathing and feeding, or emotional and spiritual support, such as listening and providing companionship. These organizations offer training and support to volunteers and may also provide opportunities for volunteers to contribute to other aspects of palliative care, such as fundraising, advocacy, and public education. Good quality home care services, with participation of family and trained volunteers can help in reversing the present trend of financially and emotionally expensive institutionalized health care models. In addition, it can free up hospital beds for much needed emergency care.



Fig.1.9: THE TRAINED VOLUNTEERS IN KERALA TRANSPORTING A PERSON IN THE APPROPRIATE MANNER ACROSS A DIFFICULT TERRAIN

#### **Differences Between Conventional and Palliative Care Approaches**

Usually, healthcare professionals focus on physical problems – organs and diseases. Palliative care recognizes that people are much more than their organs; their minds, spirits, and emotions are all part of who they are. It also acknowledges the families and communities to which they belong. So, the problems a sick person faces, and their family are not just physical; there may be a psychological, social, and spiritual concern that is as important as any other problem. Sometimes problems in one area may worsen other existing issues; for example, pain is often worse when anxious or depressed. Only when we address all these aspects, our care can be helpful to the patient. Let us focuson what we can do to care rather than be discouraged by what we cannot cure. This holistic

approach distinguishes Palliative care from conventional medical care. Palliative care is not primarily aimedat the length of life. Still, improving quality of life so that the remaining time, be it days, months, oryears can be as comfortable, peaceful and fruitful as possible.



#### Fig.1.10: DIFFERENCE BETWEEN THE OLD AND NEW CONCEPT

Conventional approach	Palliative approach
• The disease is the central concern.	<ul> <li>Human dignity is the central</li> </ul>
<ul> <li>The physician is the general</li> </ul>	<ul> <li>The patient is sovereign.</li> </ul>
■ Intent – curing.	<ul> <li>Intent – healing</li> </ul>
• The disease is a problem to besolved.	• The disease is an experience to be lived.
<ul> <li>"Don't just be there, do something."</li> </ul>	<ul> <li>"Don't just do something be there."</li> </ul>
• The goal is to improve the quantity of life.	<ul> <li>The goal is also to ensure life and dea with dignity.</li> </ul>
<ul> <li>Death: A failure of treatment to be prevented at all costs.</li> <li>The valuable approach in caring foracute price discusses</li> </ul>	<ul> <li>Death: An inevitable reality, neither to l hastened nor postponed at the cost quality of life</li> <li>The us hashes arrange him series for shreet</li> </ul>
episodic diseases.	<ul> <li>The valuable approach in caring for chron progressive disease.</li> </ul>

## Table 1.1 – COMPARISON OF CONVENTIONAL BIO-MEDICAL AND PALLIATIVE CARE APPROACHES

### **Ethical Aspects in Palliative Care**

Palliative care providers meet many issues and ethical dilemmas while caring for patients; are we in the right way? Can this intervention improve the quality of life of our patients? This can only be solved by understanding ethical principles and precedents, which will help us decide whileproviding care to them. Ethics in palliative care provides guidelines and codes for the PC provider's duty, responsibility, and conduct. As we practice Nightingale Pledge as the guiding principle in nursing,

similarly, doctors use the Hippocratic Oath. Modern medical ethics was developed in the Nuremberg Code. In 1948 the Declaration of Geneva gave the laws and policies; it was modified in 2006 and, in 1964, incorporated in the Declaration of Helsinki, and the latest modification was made in October 2008. Nurses in palliative care settings must be familiar with their legal, ethical, and professional obligations.

There are a variety of legal and ethical issues relevant to the palliative care nursing context:

- Confidentiality
- Right to refuse
- Competence and ability
- Proxy decision-making
- Euthanasia or 'assisted suicide'
- The provision of artificial nutrition and hydration
- Withholding or withdrawing other life-prolonging treatments
- Organ and/or body donation

As you have seen throughout this section, various legal and ethical issues are relevant to thepalliative care nursing context. In all nursing contexts, including palliative care nursing, ethical decisions are based on several key concepts:

- Autonomy: a commitment to enabling patients to make decisions in their best interests. This involves respecting what a patient considers to be in their best interests, provided they can decide on and communicate this.
- Beneficence: It is doing good for the patient and relevant others
- **Non-maleficence**: It is no harm to the patient or appropriate others. This involves weighing therapy's possible harms and anticipated benefits to decide what is best.
- Justice: ensuring the care provided to a patient is fair and equitable.

And other two critical principles are:

- 1. **Dignity -** the patient and the persons treating the patient have the right to dignity.
- 2. Truthfulness and Honesty the concept of informed consent and truth-telling

World Health Organization (WHO) and various national bodies/associations of palliative care, with their continuous effort in most countries, have taken steps to ensure that relief from painis a legal right and availability of Morphine is a societal responsibility. Everyone who needs palliative care should never be denied. It will be considered a violation of human rights. Therefore, as PC providers, we need to manage their concerns like pain and symptom control, psycho-social care, and end-of-life issues while respecting their dignity, and ethical care must be provided.

## Need for Palliative Care in India

- Less than 4% of India's 1.3 billion people have access to palliative care.
- One in five suicides in India is committed by a person living with a progressive, chronic, or lifelimiting condition.
- Every year, catastrophic health expenditures push fifty-five million people below the poverty line in India.
- While the lower-income groups suffer significantly due to the above reason, paradoxically, the affluent in our country are also marginalized due to the absence of palliative care in healthcare institutions, including the government and private sectors.
- Millions of people cannot access a healthcare facility because they are bed-bound or elderly and

living alone with no one to accompany them. Care must reach their homes.

- Socially and culturally marginalized groups women, children, the Lesbian, gay, bisexual, and transgender (LGBTQI) community, people with mental health conditions, migrant populations, prisoners, and geographically isolated groups –are often forgotten. Equitable care must reach people, whoever they are, wherever they are, whenever they need it.
- There is a huge need for palliative care in India. Out of the 7 million people who die yearly, over 5 million need palliative care, but less than 4% get palliative care. There are 2.8 million new cancer cases every year. Two-thirds of these are incurable when they reach the hospital, and 70 to 80% have severe pain. Almost 80% of hospitalized HIV/AIDS and 40 to 50% of heart failure patients have moderate to severe pain. Unfortunately, less than 4% of patients get proper pain relief.
- According to the WHO guideline, palliative care is integral to COVID-19 management.

#### Health conditions that may need palliative care

People of any age whose health condition commonly result in death or suffering need palliative care. Remember: palliative care is provided to people with one or more medical conditions which are: (1) active, (2) progressive, and (3) unlikely to be cured. Today, palliative care can be applied to many serious or life-threatening conditions, whether terminal or non-terminal. As highlighted earlier in this section of the chapter, there are a variety of conditions for which a person may be palliated:

- Cancer
- Diseases involving failure of the organs
- Neuro-degenerative disorders like Alzheimer's disease, Parkinson's disease, Multiple Sclerosis (MS), and Amyotrophic Lateral Sclerosis (ALS)
- Incurable diseases
- Congenital conditions
- Severe traumatic injury
- Old age
- Palliative care is also essential for some patients with COVID-19

The goal of palliative care is to improve the quality of life. It is essential to understand that palliative care is not provided to a person only during the days or hours before their death. The care starts from the time of diagnosis of such health conditions mentioned above.

#### When is Palliative Care Appropriate?Simultaneous therapy

Palliative care works alongside and within other treatment regimes. It does not replace other forms of care. It ought to be integrated into existing comprehensive care of different disease programs. It should be seen as a part of a continuum of care given to everyone with a life-limiting illness.

Many hospital programs, such as comprehensive cancer care centers with chemotherapy or radiotherapy services, HIV clinics, and super-specialty centers, are competent in providing disease interventions but not well-trained in helping patients with symptom relief and psycho-social problems such as anxiety, grief, isolation, and stigma. This often leaves the patient unsupported and may influence compliance with curative inputs. When integrated into such programs, Palliative care can complete the care inputs and improve compliance with treatments and overall outcomes.

Palliative care should accompany curative measures, providing medical management of complicated symptoms and side effects and giving social, emotional, and spiritual support to the patients and their family. The requirement for palliative care enhances visibly during critical transition phases in the disease trajectory. For example, in cancer, as given below, the need for palliative care can be perceived at different stages of the disease, and the inputs required may be variable. With the progress of the disease, the person's needs may change, and palliative needs may overshadow curative treatment.

#### At diagnosis

There is an increased need for communications here. It is essential to communicate effectively with patients and family, provide symptom control and maximize support to help complete curative therapy.

E.g., clarifications on the cancer diagnosis, the impact of that cancer, available interventions and adverse effects of interventions, and expectations of cure are all to be discussed with the patient for decision making.



#### Fig.1.11: CONTINUUM OF CARE

#### Post cure phase

This is a phase with heightened anxiety, where the patient needs adequate information to clarify doubts and fears and support their genuine concerns. Due to the curative therapy, a few distressing symptoms, e.g., lymphoedema of the arm post-mastectomy, shoulder pain syndrome after radical neck dissection, etc., may need competent long-term management.

#### At recurrence or when cancer becomes unresponsive to disease-modifying therapies

Here the symptoms and psycho-social concerns keep increasing due to progressive disease. The patient and family require regular medical, nursing, and counselling while facing complex issues during illness.

#### **Terminal phase**

Here the emphasis would be to allow a dignified, peaceful, and symptom-free dying without burdening family resources.

#### **Bereavement support**

After the death of a loved one, it may take many months for family members to accept their loss and rebuild their life. Supporting them through this process is an essential part of palliative care.

#### **Skills Required by Nurses in Palliative Care**

Some skills that are important for a palliative care nurse include:

- 1. **Communication skills:** Palliative care nurses need to be able to communicate effectively with patients and their families to understand their needs, preferences, and concerns. They must also be able to communicate with other healthcare professionals to coordinate care and provide updates on the patient's condition.
- 2. **Clinical skills:** Palliative care nurses must have a solid understanding of their patients' medical conditions and treatments. They must be able to assess the patient's condition, monitor symptoms, and provide appropriate interventions to manage symptoms.
- 3. **Pain and other symptom management skills:** Pain is a common symptom for patients receiving palliative care. Palliative care nurses must have expertise in pain/other symptoms management techniques, including medication administration, non-pharmacologic interventions, and pain assessment tools.
- 4. **Emotional support skills**: Patients and their families may experience a range of emotions during palliative care, including fear, anxiety, and grief. Palliative care nurses must be able to provide emotional support and counselling to patients and families to help them to cope with these emotions.
- 5. **Cultural competence:** Palliative care nurses must have an understanding of cultural differences and how they can impact a patient's care. They must be able to provide care that is sensitive to the patient's cultural beliefs and values.
- 6. **Teamwork and collaboration:** Palliative care nurses work as part of a team of healthcare professionals, including physicians, social workers, and chaplains. They must collaborate effectively with other team members to provide comprehensive care to patients and their families.
- 7. Advocacy skills: Palliative care nurses must be able to advocate for their patients and ensure that they receive the care and support they need. They must also be able to advocate for their patients' families and help them navigate the healthcare system.

#### Conclusion

Palliative care aims to relieve symptoms and improve the quality of life of people with serious or life-threatening illnesses. It may be included as a part of hospice care, but it is not the same thing as hospice care. With palliative care, you can still receive care whether your condition is terminal.

A team that includes medical and allied health professionals delivers palliative care to patients. The team also address the person's emotional, practical, and spiritual needs. The criteria for palliative care services can vary by the medical condition, the health status of the individual, and other factors. But it is ultimately aimed at bringing comfort to people faced with severe illnesses of many types. As nurses, we will likely meet people in various settings who may benefit from palliative care and support.

## **Activity for Unit 1**

#### I. Answer the following in one or few words

- 1. Who was the founder of the modern palliative care movement?
- 2. Where was the first modern hospice started?
- 3. What is the ideal time to start palliative care?

#### II. True or False

- 1. Palliative care cannot be provided at home.
- 2. Palliative care is to improve the quality of life of patients and families.
- 3. In India, less than 4% of people only have access to palliative care.
- 4. Terminal care and palliative care are the same.

#### **III. Short answers**

- 1. What is palliative care?
- 2. List the type of patients who require palliative care.
- 3. What are the dimensions of palliative care?
- 4. Describe the concept of palliative care.

#### IV. Group- activityObjectives:

To reinforce the principles of palliative care.

#### Activity instruction

Students will be facilitated with the case scenario and advised to discuss it.

**Case scenario I**: A 50-year-old woman with advanced ovarian cancer stays in your neighborhood. She has two daughters, aged 24 and 16; the elder daughter is away with her husband. The treating doctor has told the patient's husband that her disease is not responding to curative therapy, and the patient is likely to die within the next 6-9 months. You visited her yesterday. She complained of pain all over her body, and she looked apprehensive.

- 1. What can you do to help this patient and her family?
- 2. Who else can support this patient?

## Unit 2 COMMUNICATION SKILLS

#### Introduction

Communication is exchanging ideas or feelings between two or more people on a common background or agenda. Communication can be verbal or non-verbal. The communication process is complex, and more than 70% of communication occurs through non–verbal means.

Good communication is a trainable skill. Proper communication is vital for the well-being of the patient and the family and satisfaction from work. Studies show a significant unmet communication need for information about the disease, prognosis, treatment options, intent, side effects, and complications.

#### **Effective communication**

Good clinical communication will help the patient to express his needs to the treating team better. It helps clarify doubts and baseless apprehensions. The therapeutic rapport that develops through effective communication supports the patient and family in managing the emotional responses to the illness and dealing with the uncertainty.

It helps the nurse understand the symptoms, their sequences, and their impact on the patient's quality of life and clarifies the clinical condition. Thus, the nurse understands the shared and balanced decision to be evolved based on the patient's values, beliefs, and priorities yet supported by clinical evidence and rationale from a caring treating team.

Effective communication is crucial in palliative care to ensure that patients and their families receive the care they need and meet their physical, emotional, and spiritual needs. Here are some tips for effective communication in palliative care:

- **Build rapport:** Take the time to establish a relationship with the patient and their family members. Listen actively, show empathy, and demonstrate that you care about their wellbeing.
- Use simple language: Avoid medical jargon and plain language that is easy for the patient and their family members to understand.
- **Practice active listening:** Listen carefully to what the patient and their family members say. Encourage them to share their feelings and concerns and validate their experiences.
- **Be honest and transparent:** Provide clear and accurate information about the patient's condition, prognosis, and treatment options. Avoid withholding information or providing false hope.
- **Respect cultural and spiritual beliefs:** Take the time to understand the patient's cultural and spiritual beliefs and respect their preferences for care.
- **Collaborate with the healthcare team:** Work collaboratively with other healthcare team members to ensure that the patient's physical, emotional, and spiritual needs are met.
- Use appropriate body language: Use appropriate body language to convey empathy and understanding, such as making eye contact and nodding in agreement.
- Ensure privacy and confidentiality: Ensure that the patient's privacy and confidentiality are respected, and that sensitive information is not disclosed to others without the patient's consent.

### **Need for Effective Communication**

Effective communication is essential in palliative care for several reasons.

- 1. Patient-centered care: Palliative care is focused on the patient's needs and goals, and
  - effective communication is crucial in understanding and addressing those needs and goals.
- 2. Quality of life: Palliative care aims to improve the patient's quality of life, and effective communication helps healthcare providers to

understand the patient's physical, emotional, social and spiritual needs and tailor care accordingly.

3. **Decision-making:** Effective communication is essential for shared



Fig.2.1: NURSE PATIENT COMMUNICATION

decision-making between the patient, their family members, and the healthcare team. It helps ensure that decisions are made that align with thepatient's preferences and values.

- 4. **Symptom management:** Effectivecommunication helps healthcare providers identify and manage symptoms, such as pain and nausea, that can significantly impact the patient's quality of life.
- 5. **Emotional support:** Palliative care is often a time of emotional distress for patients and their families, and effective communication can provide emotional support and comfort.
- 6. **Coordination of care:** Effective communication helps ensure that the patient's care is coordinated across different healthcare providers and settings, such as hospitals, hospices, and home care.

#### What if we fail to communicate?

- It may lead to poor symptom control.
- The patient may not follow the plan of care as their needs/agendas have not been discussed and supported.
- The adjustment to the illness and interventions would be poor, and this can lead to worsening distress.
- There can be situations with escalating conflict.
- The team that does not communicate effectively may find an enquiring patient 'too demanding.' This can affect the therapeutic relationship.
- Medico-legal problems stem primarily from poor communication, and misperceptions and misunderstandings may ensue.

#### Aims of effective communication in a Nurse - Patient relationship

- Reduce uncertainty
- Enhance relationship
- Prevent unrealistic hope
- Allow proper adjustment
- Provide personal satisfaction
- Guide and give direction

#### • Communication Skills

Effective communication skills are essential for nurses, who are critical in providing high-quality patient care. Nurses must be able to communicate effectively with patients, families, and other healthcare providers to ensure that the best possible care is delivered. Nurses need to acknowledge and understand the concerns of the patient and family and respond appropriately to bring clarity to their current situation.

Effective communication is crucial in palliative care, where nurses are vital in supporting patients and families through the end-of-life journey. Here are some core communication skills for palliative care nurses:

- Active listening: Nurses should listen attentively to patients, family members, and other healthcare providers to understand their concerns, fears, and needs fully.
- **Empathy:** Nurses should be able to understand and relate to the emotions and feelings of their patients and their families, providing comfort and support.
- Clear and concise communication: Nurses should be able to communicate clearly and concisely with patients and their families, using appropriate tone and language. They should also use plain language to explain complex medical information.
- **Non-verbal communication:** Nurses should be aware of their body language, facial expressions, and gestures, which can convey more information than words alone.
- **Open and honest communication:** Nurses should be open and honest with patients and their families, discussing end-of-life issues, including pain management, palliative sedation, and withdrawal of treatment.
- **Culturally sensitive communication:** Nurses should be aware of cultural differences and be able to communicate effectively with patients and their families from diverse backgrounds.
- **Conflict resolution:** Nurses should be able to manage disagreements and conflicts between patients, families, and healthcare providers in a respectful and constructive manner.

#### **Core Principles of Communication**

These principles can help nurses to communicate effectively and achieve their goals, whether it is to build strong relationships, resolve conflicts, or achieve success in the workplace.

- **Respect:** Respect involves treating others with dignity and recognizing their worth. It involves valuing their opinions and ideas, even if they differ from our own. Respecting others' boundaries, cultural backgrounds, and beliefs is critical in building positive relationships and fostering open communication.
- **Empathy:** Empathy is the ability to understand and relate to the feelings, thoughts, and experiences of others. It involves putting ourselves in another's shoes and seeing things from their perspective. Empathy helps to build trust and strengthen relationships by demonstrating our willingness to understand and support others.
- **Trust:** Trust is the foundation of all healthy relationships. It involves having confidence in others' integrity, reliability, and ability to meet our expectations. Trust is built over time through consistent and transparent communication and by keeping our commitments.
- Unconditional positive regard: Unconditional positive regard involves accepting and valuing others for who they are, regardless of their thoughts, feelings, or behaviors. It involves seeing the good in others and treating them with kindness and compassion. Unconditional positive regard helps to create a safe and supportive environment where individuals feel accepted, valued, and respected.

Every patient has different communication needs, which may change throughout their illness.

#### **Consequences of poor communication**

Poor communication in palliative care can have significant negative consequences for patients, families, and healthcare providers. Some of the consequences of poor communication in palliative care may include:

- 1. **Increased anxiety and distress:** Patients and families may feel anxious, confused, and uncertain about their medical condition, prognosis, and treatment options if they do not receive clear and accurate information from healthcare providers.
- 2. **Inadequate pain and symptom management:** Poor communication between healthcare providers may result in inadequate pain and symptom management, leading to increased suffering and decreased quality of life for patients.
- 3. **Reduced patient satisfaction:** Poor communication can lead to reduced patient satisfaction and trust in healthcare providers, potentially leading to patients and families seeking care elsewhere.
- 4. **Conflict and disagreements:** Poor communication can result in misunderstandings and disagreements between patients, families, and healthcare providers, potentially leading to conflict and ethical dilemmas.
- 5. **Increased burden on family caregivers:** Poor communication can result in family members feeling unprepared and overwhelmed with the responsibilities of caregiving, leading to increased stress and burnout.
- 6. **Increased healthcare costs:** Poor communication can lead to repeated hospitalizations, unnecessary medical interventions, and increased healthcare costs.

#### **Barriers to effective communication**

Professional versus social dialogue: Unlike social interactions, any form of professional dialogue would have an implicit contract between the professional and the patient. This differentiation brings forth a unique set of barriers and problems for professionals during communication with the patient. Professional problems in communicating with patients:

- Fear of upsetting the patient
- Fear of causing more harm than good
- Unsure about answering difficult questions
- Afraid of saying, "I don't know."
- Patient's belief that health professionals are too busy
- Unable to manage patient's emotions
- Unable to improve the situation
- Fear of the untaught
- Fear of being blamed

#### Patient's problems in communicating with health professionals

Patients -

- think that the health professionals are too busy.
- think that they are more interested in their physical care.
- they do not want to know about any emotional problems.
- are frightened to complain in case they stop treating them.
- are frightened of going out of control.
- may be terrified of having the truth revealed.

#### The problems arising in communication

- Pretending to be busy
- Selective attention to safe physical aspects
- Not exploring beyond physical issues
- Premature/false reassurance
- Premature normalization
- Jollying along
- Inappropriately introducing humor
- Concentrating on physical tasks
- Using euphemisms to mislead
- Disappearing from the stressful situation
- Patronizing and talking down to patients
- Using medical jargon
- Distancing behaviors

#### Examples of good and poor communication techniques

#### 1. Ask for open techniques!

**Nurse** *"Is your pain better today?* This closed question gives either a yes or no answerand needs revision.

#### Nurse: "How are you feeling?"

This allows the patient to open up and vent their feeling.

#### 2. Be empathetic

Patient: "I feel scared when I am breathless."

*Nurse: "Take these tablets to ease your breathing".* Here, the nurse has ignored the patient's emotions, which is wrong.

#### The correct approach would be.

Patient: "I feel scared when I am breathless."

**Nurse:** "Breathlessness can be very frightening. It is very understandable. I shall give you the prescribed medicines which should help you." OR

Nurse: "What scares you most when you get breathlessness?"

#### 3. Be sensitive while telling the truth

Patient: "The doctor said my cancer is incurable."

*Nurse: "Don't worry about such things. Everything will be okay".* Here, the nurse is giving false reassurance, which is not the correct approach.

#### A better statement would be as follows.

**Nurse**: "It must have been tough to hear that cancer has spread, but we will do our best to help you however we can."

#### 4. Always try to balance hope and truth

Nurse: "There is nothing more we can do; your disease is incurable, so there is no point in staying in the hospital." Here the nurse is destroying hope, which is incorrect.

The nurse should try to balance hope and truth.

**Nurse:** "I am sorry that no more treatments are available to cure your disease, but we can start other medicines to make you more comfortable. Then you can be at home with your family. If you need any help in future, you must come to the clinic or contact me."

#### 5. Keep confidentiality and avoid unhealthy curiosity

**Patient:** I have not told anybody before, but I got this cancer because I had an abortion when I was seventeen."

Nurse: "Were you not worried at that time." Here the nurse is getting curious about the irrelevant matter.

#### The right approach would be as

**Nurse:** "We need to discuss this more, as it is incredibly significant for you, but please know that everything we discuss will be kept confidential."

The nurse here assures confidentiality, and at the same time, he would like to have more details which would be medically significant.

#### 6. Partnership between nurse and patient

Nurse: "You must take this medicine for your pain. Unless you accept this, your painwill remain as such. The nurse is imposing their agenda on the patient, which is wrong.

**Nurse:** "Your pain is caused by the disease, and you need pain medicine. How about trying it?"

Here the nurse is trying to set up a bond with the patient by soliciting his opinion.

#### Nonverbal communication

Nonverbal communication is an important aspect of communication in palliative care, as it can convey emotions, empathy, and understanding. Non-verbal communication: Non-verbal communication is featured by mode and tone of voice with which words are spoken; gestures going with the speech; looks and facial expressions; physical contact, touch, body posture, pitch and pace of voice, and active listening.

Here are some examples of nonverbal communication in palliative care:

- Eye contact: Making eye contact with the patient and their family members can convey empathy and understanding, and can help to establish a rapport.
- Facial expressions: Facial expressions, such as a smile or a nod, can convey empathy, understanding, and support.
- **Touch:** Appropriate touch, such as holding a patient's hand or giving a hug, can convey compassion and comfort.
- **Body language:** Body language, such as leaning forward or sitting at the same level as the patient, can convey attentiveness and interest.

- Silence: Silence can be a powerful tool in palliative care, allowing patients and their family members time to process their emotions and thoughts.
- **Tone of voice:** The tone of voice can help to convey empathy, understanding, and support. A gentle tone can help convey a caring attitude, while a rushed or dismissive tone can convey impatience and lack of concern.
- Environment: The environment can also convey nonverbal communication. Creating a calming and welcoming environment can convey support and empathy.
- It's important for nurses in palliative care to be aware of their nonverbal communication and to use it in a way that conveys empathy, understanding, and support to patients and their family members.

## Learning to communicate with patients having advanced and progressive diseases

Communicating with patients who have advanced and progressive diseases in palliative care can be challenging, but it is essential for providing compassionate care. Effective communication with patients facing progressive disease, with complex problems and an uncertain future, is challenging and needs more skills and practice. Patients with advanced and progressive diseases have issues other than physical, and they require compassionate listening and empathetic responses. Here are some tips for effective communication:

- Use simple language: Use plain and straight forward language to ensure that patients can understand you easily.
- **Be honest:** Be honest and transparent about the patient's condition, prognosis, and treatment options.
- Listen actively: Listen carefully to the patient's concerns and feelings, and encourage them to share their thoughts.
- Show empathy: Show empathy and understanding towards the patient's emotional andphysical challenges.



Fig.2.2: COMMUNICATING WITH PATIENTS HAVING ADVANCED DISEASE

- **Respect the patient's autonomy:** Respect the patient's autonomy and allow them to make decisions about their care to the extent that it is possible.
- **Provide support:** Provide support to patients and their families to cope with the changes that come with the advanced and progressive stages of the disease.
- **Collaborate with the healthcare team:** Work collaboratively with other healthcare team members to ensure that the patient's physical, emotional, and spiritual needs are met.
- Use nonverbal communication: Use nonverbal communication, such as touch, eye contact, and facial expressions, to convey empathy and understanding.

- Avoid false hope: Avoid providing false hope or unrealistic expectations, and instead focus on providing comfort and symptom management.
- **Consider cultural and spiritual beliefs:** Consider the patient's cultural and spiritual beliefs when communicating and providing care.

By using these strategies, healthcare providers can communicate effectively with patients with advanced and progressive diseases in palliative care and provide compassionate care that meets their physical, emotional, and spiritual needs.

#### **Basics steps of communication**

- i. Preparing for listening
- ii. Questioning
- iii. Listening effectively (facilitating) shows that you have heard
- iv. Responding

#### i. Preparing for listening

It is essential to practice **active listening** as it is the key to effective communication.

Active listening: involves fully focusing on the speaker and attempting to understand their message. This includes paying attention to the speaker's verbal and nonverbal communication, asking clarifying questions, and providing feedback. Active listening requires the listener to be fullyengaged in the conversation, to concentrate on what is being said, and to be present in the moment. Active listening is important in palliative care, as it can help healthcare providers to understand thepatient's needs and concerns and provide appropriate care.

**Passive listening:** on the other hand, involves listening without actively engaging in the conversation. The listener may appear to be listening but is not fully focused on the speaker's message. Passive listening may involve nodding, making eye contact, or saying "mm-hmm" without really paying attention to the content of the message. Passive listening can lead to misunderstandings, miscommunication, and missed opportunities for building rapport with patients and their families.

The following methods help to enhance listening skills.

- **Greeting and seating:** Allow the patient to take their comfortable position in the bed or chair. Provide privacy and sit beside the patient at a reachable distance without any barrier between the patient and yourself.
- Ask open questions: Open-ended questions give freedom to the patient to decide what andhow much they should tell.
- **Encourage talking:** To get more details and develop better rapport, it is good to encourage the patient to talk about his concerns.
- Maintain eye contact: It gives confidence to the patient that they are being actively listenedto.
- **Tolerate brief silence:** Silence can have diverse meanings in communication. It can be understood as a time to think, consider a response, or express emotions.
- Avoid unnecessary interruptions: Interruptions should not be too frequent in a way that affects the flow of communication.
- Show them that they are listened to: The patients should feel that they are being heard by verbal and non-verbal means. This can be done by repetition, reiteration, and reflection.
- **Summarize and prioritize the agenda**: We must summarize and explain the treatment planand help them with shared decision-making.
- **Empathize and give realistic hope.** Nurse have to approach the patients with empathy and to provide realistic hope.
#### ii. Questioning

Questioning is an important aspect of communication that involves asking questions to gather information, clarify understanding, and encourage dialogue.

There are several types of questions that can be used in communication, including:

- Open-ended questions: These are questions that require more than a simple yes or no answer. They encourage the speaker to provide more detailed information and can help to facilitate conversation and encourage the exploration of thoughts and feelings. Example: "What brings you to palliative care today?"
- Closed-ended questions: These are questions that can be answered with a simple yes or no. They can be useful for getting specific information but may not encourage further conversation. Example: "Have you experienced any pain today?"
- 3. Leading questions: These are questions that are phrased in a way that suggests a particular answer. They should be avoided as they can bias the response. Example: "You're not experiencing any pain today, are you?"
- 4. **Clarifying questions:** These are questions used to gain a better understanding of the speaker's message. They can be useful for ensuring that the listener has understood the speaker's meaning. Example: "Can you explain what you mean by 'feeling anxious'?"
- 5. **Reflective questions:** These are questions used to reflect back the speaker's message to show that the listener has understood. They can be useful for building rapport and showing empathy. Example: "It sounds like you're feeling overwhelmed by the situation. Is that correct?"
- 6. Hypothetical questions: These are questions used to explore potential future scenarios or situations. They can be useful for decision-making and problem-solving. Example: "What would you like to do if your pain becomes too difficult?"

In palliative care, open-ended, clarifying, and reflective questions may be particularly useful for building rapport with patients and their families, understanding their needs and concerns, and providing appropriate care.

There are several key principles of questioning in communication that can help to promote effective communication:

- 1. Use open-ended questions: Open-ended questions allow the speaker to provide more detailed information and encourage further conversation. They are useful for building rapport and understanding the speaker's perspective.
- 2. Avoid leading questions: Leading questions suggest a particular answer and can bias the response. They should be avoided in communication.
- 3. Use clarifying questions: Clarifying questions help to ensure that the listener has understood the speaker's message. They can be used to gain a better understanding of the speaker's perspective.
- 4. **Use reflective questions:** Reflective questions reflect back the speaker's message to show that the listener has understood. They can be used to build rapport and show empathy.

- 5. **Avoid interrupting:** Interrupting can be seen as disrespectful and can hinder effective communication. It is important to allow the speaker to finish their thought before responding.
- 6. **Be aware of nonverbal communication:** Nonverbal cues such as tone of voice and body language can impact the effectiveness of questioning. It is essential to be aware of these cues and use them to guide the questioning process.

Effective questioning can help nurses to understand the patient's needs and concerns, provide appropriate care, and build rapport with the patient and their family. It is important to usequestioning techniques that are respectful, empathetic, and focused on understanding the patient's perspective.

#### iii. Listening effectively (facilitating) shows that you have heard

Listening effectively and facilitating a conversation involves more than simply hearing the speaker's words. It involves actively engaging in the conversation, demonstrating empathy, and providing feedback to show that you have understood the speaker's message.

The listening wheel can be followed to show that you are listening.

- **Open Questions:** How? What? Where? Who? Why?
- **Summarizing:** A summary helps to show the individual that you have listened to and understood their circumstances and feelings.
- **Reflecting:** Repeating a word or phrase encourages the individual to continue and expand.
- **Clarifying:** Sometimes, an individual may gloss over a crucial point by exploring. These areas further, we can help them clarify these points for themselves.
- Short Words of Encouragement: The person may need help to go on with their story –use words like 'yes' or 'go on.'
- **Reacting:** We need to show that we have understood the situation by reacting to it "*That it sounds like it is exceedingly difficult.*"





#### Effective listening and facilitating: Ten Commandments

- 1. **Stop talking:** The first commandment of good listening is to stop talking and start listening
- 2. Put the speaker at ease: The patient can organize his thoughts and convey them meaningfully only when put at ease.
- 3. Show them that you want to listen and maintain eye contact: The nurse should make it clear that they are attentive and keen to receive the message. This may be done by appropriate body movement or proper posture.
- 4. **Remove distractions:** The nurse has to remove distractions, if any, such as shutting the door, switching off the cell phone and removing objects between the patient and the nurse so that body movements can be observed.
- 5. **Empathize with them:** An essential requirement for effective listening is that the nurse should show empathy or proper understanding.
- 6. Be patient and tolerate short silences: wait for the speaker to complete the talk. The nurse

should avoid frequent interruptions, derogatory remarks, negative comments, and distracting gestures.

- 7. **Hold your temper:** The nurse may not appreciate the communicator's message. That does not give the nurse the right to instant reaction.
- 8. **Don't argue or criticize:** The nurse should not challenge and blame the patient. Any such argument or criticism would be detrimental to the flow of communication.
- 9. Ask questions: Positive interventions by the nurse are desirable. The nurse should ask appropriate questions at the right opportunity to elicit more information.



**Fig.2.4: LISTENING TO PATIENT** 

10. **Stop talking:** For speaking to progress smoothly, talking should be stopped by the nurse and keep listening.

#### The benefits of effective listening

- Build trust and strong relationships
- Helps to resolve conflict
- Prevents missing valuable information
- Enables us to find or expect problems
- Helps to build more knowledge

#### iv. Responding

Effective responding in palliative care communication is important to ensure that the message is received and understood. Here are some key principles of responding in communication:

- Acknowledge the message: Start by acknowledging the speaker's message to show that you have heard and understood what they have said.
- **Provide feedback:** Provide feedback to the speaker to show that you are engaged in the conversation. This can be in the form of nodding, making eye contact, or providing verbal cues such as "I see" or "I understand."
- **Reflect on the message:** Reflect on the speaker's message to show that you have understood their perspective. This can be done summarizing what has been said or paraphrasing the message in your own words.
- **Show empathy:** Demonstrate empathy by acknowledging the speaker's feelings and validating their perspective. This can help to build trust and rapport.
- **Respond appropriately:** Respond appropriately to the speaker's message. This may involve providing information, offering support, or asking further questions to clarify understanding.
- Avoid interrupting: Avoid interrupting the speaker as it can be seen as disrespectful and can hinder effective communication.

#### Tips for responding to create a supportive helping relationship

- Respond in a way that focuses attention on the issues and concerns: clarify inconsistencies and gather facts quickly and unobtrusively.
- Probe with open-ended statements to gain more information. Use Tell me more about ..., Let us talk about that, or I'm wondering about ... Responding in this manner is usually more effective than using specific who, what, when, where, and why questions.
- Ask for clarification, e.g., I am having trouble understanding what you're saying. Is it that ...? Or could you review that again, please?
- Use understandable words. Listen to the vocabulary of the other person to get a clue to their level of understanding.
- Try not to preach, blame, or be demanding.
- Try to avoid straying from the topic!
- Show understanding and sincerity in your responses, so the patient will feel comfortable discussing more information.
- Try not to talk excessively about yourself. Keep self-disclosure to a minimum!
- Give responses proper for the age, sex, and emotional state of the patient!
- Be comfortable with silence. Do not feel that silence needs to be filled with talk!
- Try to remain neutral and nonjudgmental in responding to actions, comments, or conditions you find antagonizing, shocking, or hostile.
- If you become tangential (straying from the topic), try to refocus the discussion.
- If people become emotional and cry, allow them to call. Show respect. Do not stop them but try to make them feel comfortable while crying.
- Use responsive body language: make eye contact, and lean forward.

In palliative care, effective responding is important to ensure that the patient's needs and concerns are addressed, and that appropriate care is provided. It is important to use responding techniques that are respectful, empathetic, and focused on understanding the patient's perspective. By demonstrating empathy, active listening, and appropriate responses, healthcare providers can promote effective communication and build trust with patients and their families.

#### What is not recommended during clinical communication?

1) **Do not at once reply** to the patient's words. It is helpful to enquire about feelings or real questions behind the patient words.

**E.g.**, When a patient asks... "Sister, how long do I have?" the implicit question usually is "Sister...now that I have very little time left, what can I expect? How can you help me?"

2) Do not use philosophies or moralize. They may hurt the patient's feelings and stop the further conversation.

E.g., "You should not say such things. God gave your life. Trust in God."

3) Avoid comparisons. It is insensitive to say that someone else's grief is more significant; therefore, the patient has no right to grieve.
E.g., "Look at that man over there. He has no family; he is alone and in pain. At least be thankful that you have a loving family."

- 4) Avoid meaningless words. E.g., "*There is nothing to be afraid of.*"
- 5) Avoid medical words. They are jargon from the patient's point of view. Technical language tends to overwhelm patients.

6) Avoid false reassurance.

**E.g.**, *"When your general health improves, we shall try more chemotherapy. That will cure you.*" It does not provide comfort, and it destroys trust. Reassurance is essential to keephope after due interactions and explanations, but it must be based on truth.

- 7) Do not make assumptions. Check the patient's insight about the diagnosis and prognosis and what it means to her.
   E.g., "What made you ask that question?"
- 8) **Avoid a condescending attitude**. The patient will be open to you only if you deal with them respectfully.
- 9) Do not force your beliefs or convictions on the patient.
   E.g., "You must regularly chant for strength to endure this" is imposing your beliefs on a patient.
- 10) Avoid sympathy, which is hard to bear.

**E.g.**, "*Oh*, you unfortunate thing; it is so sad you must go through this terrible disease." Instead, convey empathy – an attempt to put us in the patient's shoes and understand what he is going through. **E.g.**, "*I can see that you are going through a lot....*"

#### 11) Avoid inappropriate humour.

E.g., "You are waiting for your final Visa? Ha, ha!". The patient himself may use humour as a coping strategy, but coming from us, it may seem insensitive.

12) **Avoid both lies and thoughtless honesty.** Lies may not be believed; even if accepted, they will destroy trust later. Also, the truth should not be disclosed like a bombshell. Truth is a powerful therapeutic tool but must be applied in the right doses at the right time.

# **COMMUNICATING BAD NEWS**

Breaking bad news (BBN) refers to the process of delivering information to a patient, family member, or caregiver that may be distressing or difficult to hear. This can include news about a serious illness, a poor prognosis, a treatment failure, or other negative developments related to the patient's health.BBN is a challenging aspect of palliative care, as it can be emotionally difficult for both the patient and the healthcare provider.

BBN is essential to communication as it takes time for the patient to accept the truth. It needs to be discussed in detail and clarified when more information is shared. It can significantly impact the patient's emotional well-being and abilityto make informed decisions about their care. It requires empathy, sensitivity, and effective communication skills to ensure that the patient and family members receive the information they need to make informed decisions and cope with the emotional impact of the news

#### We need to analyze ourselves beforehand

- Should we tell the diagnosis to the patient or not?
- If you were diagnosed with cancer, would you want to be told?
- How would you feel if your family hid the news from you?

#### Why should patients be told about their disease?

- The patients have the right to know about their disease.
- If it allows patients and families to plan their life.

- Knowing the truth allows the patients to cope with their disease.
- Reduces uncertainty.
- Avoids false hope.
- Builds trust between the patient and the physician.
- Helps complaints with treatment.

#### **Breaking Bad News**

Breaking bad news is an essential part of healthcare, but it can be a challenging and emotional experience for both patients and healthcare providers. Here are some steps to follow when breaking bad news:

- 1. **Prepare for the conversation:** Before you start the conversation, prepare yourself mentally and emotionally. Review the patient's medical history and any relevant test results, and anticipate their potential reactions and questions.
- 2. **Choose an appropriate location:** Choose a quiet and private location where you can talk without interruption or distractions. Make sure the patient is comfortable, and offer them a glass of water or tissues if necessary.
- 3. Set the tone: Begin the conversation with empathy and compassion. Be direct but compassionate, and avoid medical jargon. Ask the patient if they would like a family member or friend present during the conversation.
- 4. **Deliver the news:** Use clear and simple language to explain the diagnosis and the implications. Allow time for the patient to process the information and ask questions. Provide information about treatment options, potential outcomes, and support resources.
- 5. Address emotions: Acknowledge the patient's emotional reactions and offer reassurance and support. Allow them to express their feelings and concerns, and validate their emotions. Offer resources for emotional support, such as counseling or support groups.
- 6. **Develop a plan**: Work with the patient to develop a plan of care that aligns with their goals, preferences, and values. Involve the patient in decision-making, and offer choices whenever possible. Set realistic expectations, and provide ongoing support and communication.
- 7. **Follow up:** Follow up with the patient and their family after the conversation to answer any remaining questions, offer additional support, and monitor their physical and emotional well-being.

# **COLLUSION**

The act of shielding information from the patient or family is called collusion. Collusion in palliative care refers to the situation where healthcare providers and the patient or family members avoid discussing difficult topics such as end-of-life decisions, prognosis, or treatment options. This collusion can occur for various reasons, including the healthcare provider's fear of causing distress to the patient or family, a lack of communication skills or training, or the patient or family's reluctance toface the reality of the situation. Collusion in palliative care can have negative consequences for the patient and their loved ones, and it's important for healthcare providers and caregivers to prioritize open and honest communication and respect the patient's autonomy and wishes.

#### Collusion = "PLEASE DON'T TELL"

Collusion implies information (about diagnosis, prognosis, and medical details about the patient) being held by some and kept from significant stakeholders. The type of professional care team treating the patient and colluding with the family members is a frequent problem. In addition, withholding of information also occurs between the professional team and the patient. There are several types of collusion that can occur in palliative care:

**Family collusion**: This occurs when family members or caregivers work together to withhold information from the patient or make decisions without the patient's input. This can happen when family members feel that they know what is best for the patient, or when they believe that the patient cannot handle bad news.

**Provider collusion:** This occurs when healthcare providers withhold information from the patient or make decisions without the patient's input. This can happen when providers feel that the patient is not capable of handling the information or when they believe that the patient's family members or caregivers are better equipped to make decisions.

**Patient collusion:** This occurs when the patient withholds information from their healthcare providers or family members, or when they defer decision-making to others. This can happen when the patient feels overwhelmed or powerless, or when they are unable to express their preferences or needs.

Collusion in palliative care can have negative consequences for the patient and their loved ones, and it's important for healthcare providers, patients, and their families to work together to prioritize open and honest communication and respect the patient's autonomy and wishes.

#### **Consequences of collusion**

- The patient lacks trust in everyone close to them, including the professional team
- Unfinished business for the patient or family members
- Chronic anger
- Depression and suicidal tendencies
- Disturbed sleep patterns
- Disturbed eating patterns
- Disturbed leisure patterns
- Disturbed conversation patterns

All these factors can result in the patient losing control and entering a stage of chronic depression resulting in weakness, weight loss, and disability.

#### **Managing collusion**

- Acknowledge with family members that a collision exists.
- Speak reassuringly, for instance, by saying, "you know your brother much better than I do."
- Empathize with the difficult position the family member is in. For instance, one could say, "It must be challenging for you to maintain secrecy with the patient," or "I guess you don't normally keep important things from your brother."
- Empathize again and as often as possible to gain the family member's trust.
- Empathizing and asking a dire question. One could say, "What effect does this have on you?"

#### **Effect of Collusion**

Collusion creates an atmosphere of suspicion, poor communication, and poor relation between the patient and his family members. One is never able to remain honest. This situation gets worse as time goes by for both professional team members and family members. Communication could get stifled and scary, leading to more emotional distress and increased isolation from family members The effects of collusion in palliative care can be particularly harmful, as patients and families rely on healthcare providers to be open and honest about their condition and treatment options. Here are some of the effects of collusion in palliative care:

- Lack of informed decision-making: When healthcare providers collude, patients and families are denied the information they need to make informed decisions about their care. This can lead to decisions being made based on incomplete or inaccurate information, potentially resulting in treatments that are ineffective, unnecessary, orharmful.
- Loss of trust: Collusion can erode trust between patients, families, and healthcare providers. When patients and families discover that healthcare providers are not being honest with them, they may become suspicious of their motives and lose confidence in their ability to provide effective care.
- **Increased emotional distress**: Collusion can increase emotional distress for patients and families. When patients and families are not given the information they need to understand their condition and treatment options, they may experience feelings of confusion, anxiety, and mistrust.
- Worsened quality of life: Collusion can negatively impact the quality of life for patients and families by limiting their ability to make informed decisions about their care. Patients may receive treatments that are not aligned with their values, preferences, and goals, resulting in decreased quality of life and increased suffering.
- Legal and ethical implications: Collusion in palliative care can have legal and ethical implications, as patients have the right to be fully informed about their condition and treatment options. Healthcare providers who collude may be subject to legal action and disciplinary measures.

Overall, collusion in palliative care can significantly negatively affect patients, families, and healthcare providers. It is important for healthcare providers to be open, honest, and transparent about a patient's condition and treatment options, and to work collaboratively with patients and families to develop a care plan that aligns with their goals, values, and preferences.

Breaking collusion can be a painful and challenging task. The family members will need your support, the patient needs your help, and we, as professionals, may also need support.

# ANGER

Anger is a common emotion experienced by patients in palliative care, as well as their families and caregivers. Anger is a response to feelings of helplessness, distress, and fear. It may also be a negative result of ineffective communication between healthcare professionals and the patient/carer/ family members. Anger is often unleashed on a person perceived as close (like a spouse, close friends, or close family members) or non - threatening (usually security staff, reception staff, attenders, junior nurses, and junior doctors). It's important to acknowledge and address anger in a compassionate and empathetic manner to ensure that patients and their loved ones feel heard and supported. There are several reasons why patients and their families may experience anger in palliative care, including:

- Loss of control: Patients and their families may feel like they have lost control over their lives, as they may not be able to make decisions about their care or may have to rely on othersfor assistance.
- Fear and uncertainty: Palliative care often involves uncertainty about the future, which can be frightening and overwhelming for patients and their families.
- Unresolved issues: Patients and their families may have unresolved issues related to their illness or past experiences, which can lead to anger or resentment.
- **Pain and discomfort:** Physical pain and discomfort can also contribute to anger and frustration.

#### Approach to Anger

- The patient may direct anger at you irrespective of whether you are the source of distress. Acknowledge and name the emotion. Then address the need of the patient to be understood. E.g., "I can see that you are angry; can we sit down and talk.... tell me what you thought went wrong... I may be able to help you."
- Be calm and empathetic and use positive non-verbal throughout the conversation.
- Give the patient time to express himself.
- Allow the patient to express his emotions/feelings.
- Observe the nonverbal cues of the patient.
- Acknowledge the reasons for anger.
- Arrive at a consensus through 'participatory decision-making.'
- Summarize the conversation.
- Ask if the patient wants to add something or needs any clarification.
- Assure your continued support and follow-up after a stipulated time.

#### DENIAL

Denial is the patient's refusal to take on board the bad news. It is avoiding thoughts and feelings that are painful or that you cannot deal with. It occurs to some degree in everyone who has a serious illness. It is a shock absorber that helps you bear an overwhelming situation and cope with it. However, for some patients, denial of the illness or its severity can cause delayed diagnosis or compromised compliance with treatment. In that event, patient and sustained efforts may be required to convey at least one part of the truth to permit treatment.

#### **Denial can be a problem if the patient:**

- Does not accept the diagnosis and /or prognosis and avoids/delays treatment.
- Minimises the symptoms and implications of the illness.
- Insists on continuing with curative treatments and other measures which have been proven futile/ineffective.

Denial is a common defence mechanism in most palliative care patients. It varies in severity and pervasiveness. It has varying effects on the process of adaptation. In some cases, denial reduces anxiety, while, in others, it results in excessive delay in seeking help and poor compliance to treatment.

Questions that may give an idea about the nature of denial.

- What do you think about your illness?
- What is your understanding of the seriousness of your illness?
- What are your plans?
- Do you have another plan (Plan B) if the former is found to be not working?

#### Assessment of denial

- A cognitive evaluation is essential to rule out the possibility of any psychiatric disorders.
- Check the patient's insight set up what they know. This should include their understanding of the diagnosis, prognosis, and current treatment regime.
- Listen to the words used and observe the non-verbal communication when the patient narrates. This will tell you how much the patient knows or how he feels about the illness.

#### Approach to Denial

• Ensure that the patient's denial is not due to a lack of information, understanding, or agreement

with medical recommendations.

- Distinguish between a fact being denied (e.g., diagnosis of cancer) and implications of the fact denied (e.g., cancer will not return).
- Assess how and when the patient uses denial.
- Assess the benefits and risks of denial to the patient's psychological condition and compliance with treatment.
- If the denial is expressed by minimization of illness or lack of emotional response, it signals that the patient is frightened. Provide emotional support and discuss their issues/concerns.
- Adopt a non-confrontational approach. If the denial is causing significant problems, confrontation may only increase the use of denial.
- Finally, emphasize to patients that they will not be abandoned. They will be supported and cared for.

# Conclusion

Good communication is a skill that ensures improvement. Good communication is essential for ensuring the patient's needs are under-allowed and can be met by the healthcare team. Good communication allows the nurses to connect with the patients and those who are important to them, understand their priorities and wishes, and support them to make informed decisions about their care. Reflect on your conversations and think about what went well and what you could do better next time.

# **Activity for Unit 2**

# I. Multiple choice questions

- 1. Which of the following is most important in communication?
  - a. Asking questions
  - b. Giving advice
  - c. Listening actively
  - d. Pacifying
- 2. All the following will help in setting up a good therapeutic relationship, EXCEPT:
  - a. Active listening
  - b. Empathy
  - c. Genuineness
  - d. Judgment
- 3. Communication with a patient mostly happens through:
  - a. Verbal medium
  - b. Nonverbal medium
  - c. Written medium
  - d. Electronic medium
- 4. What should be the correct approach in communicating bad news?
  - a. Should be said to all patients
  - b. Should be told only to the family
  - c. Should be said to the patient if they express the wish
  - d. The doctor should decide whether to tell or not
- 5. While you see a patient during consultation, the patient breaks down, and you tell him that "don't worry, it will be all right". This response is:
  - a. Empathic response
  - b. Premature reassurance
  - c. Active listening
  - d. Validation
- 6. The advantage of effective communication in the nurse-patient relationship is:
  - a. Reduces certainty
  - b. Prevent realistic hope
  - c. Prevent inappropriate adjustment
  - d. Guide and give direction
- 7. When we communicate with the patient, this action means they are ready to interact:
  - a. Not responding
  - b. Having eye contact
  - c. Keeping silence
  - d. Turning opposite side
- 8. This means reviewing the main points covered in an interaction:
  - a. Reflecting
  - b. Paraphrasing
  - c. Restating
  - d. Summarizing

# II. True or False

- 1. Collusion does not create an atmosphere of suspicion.
- 2. Breaking Bad news always causes distress to patients and the person breaking the bad news.
- 3. Active listening is a crucial part of communication.
- 4. Sensitive truth-telling is harmful to patients.

# **III. Short Answers**

- 1. List the basic steps of communication.
- 2. Enumerate the nonverbal communication techniques
- 3. State the do's and don'ts in communication
- 4. Enumerate communication skills
- 5. Explain the approach to anger

# **IV.Group activity/Role Play**

#### **Objective:**

Reinforce practical communication skills!

#### **Activity instruction**

- Encourage the students to perform role play on breaking the bad news in the classroom.
- Divide the students into small groups and tell them to discuss how to communicate effectively with the patient and the caregiver's scenarios, like when the patients are in different stages of illness denial, anger, bargaining, depression and acceptance stages.

# **Role Play 1**

**Role:** Palliative Care Nurse **Patient:** Mrs Sujatha, a 40-year-old woman with terminal cancer **Setting:** Hospital room

**Question:** Mrs Sujatha has been admitted to the hospital for the third time in six months due to her worsening condition. During her previous hospital stay, she was informed that her cancer had spread and it's no longer responding to treatment. The physician has asked you to speak with Mrs Sujatha about her prognosis and end-of-life care options. Please role-play the conversation with Mrs Sujatha, considering the principles of effective communication and breaking bad news.

#### **Discussion Points:**

- Steps of breaking bad news
- Do's and don'ts in effective communication in all the stages of illness

# Unit 3

# NURSING MANAGEMENT OF SYMPTOMS

# Introduction

Patient descriptions of physical symptoms and their severity are the primary data for symptom assessment in palliative care. Exploring patients' reports of symptoms requires thoroughness, persistence, and patience, a fundamental aspect of palliative care. Symptom assessment usually involves taking a detailed history from the patient to understand the cause and severity of the symptom. Ideally, the management should be guided by a comprehensive assessment of symptoms subjectively and objectively. This helps us evaluate the significance of symptoms on patients' distress, quality of life, and survival. Effective symptom management aims to provide comfort and can potentially increase the quality of life for patients and families.

#### Holistic approach in symptom assessment and management

Holistic care focuses on the whole person, not just the condition. It looks at how the individual is dealing with the situation, their physical, psychological, social and spiritual domains of health and any issues they are experiencing. Integrating holistic/palliative care principles into routine nursing practice at the hospital and home care makes it possible to provide patients and their families with high-quality care. Symptoms are inherently subjective; hence, self-report must be the primary source of information. Detailed history-taking is important. The assessment of symptoms is a vital aspect of nursing care to provide comfort and enhance the quality of life.

#### **Principles of Symptom Assessment and Management**

- Anticipate needs: A proactive and systematic approach to symptom assessment can help anticipate patients' clinical needs and support care management.
- Assess and manage holistically: Consider which problems most affect the person's quality of life (physical, emotional, social and spiritual). Many symptoms are multifactorial, or occur in clusters, and some causes may be more or less reversible than others.
- Manage pre-emptively: Given the nature of this persons' disease, consider what problems may need to be planned for, and ensure that essential medications can be accessed when needed so that the symptoms continue to be managed. To avoid delays for example over a weekend, it is advisable to indent and ensure that medication is available within the facility prior to its being needed. This pre-emptive action is referred to as anticipatory prescribing.
- Assess and reassess frequently: Consider using simple assessment tools like the Symptom Assessment Scale (SAS) to screen for and monitor symptoms. Check for adverse effects oftreatments, as well as benefits, regularly.
  - Assess whether problems are likely to be due to reversible or irreversible causes.
  - Consider and discuss the likely burden of various treatment options (cost, difficulty of undergoing investigations, realistic improvement that might be expected etc.).
  - Consider both pharmacological and non-pharmacological management options.



# Fig 3.1: SYMPTOM ASSESSMENT SCALE (SAS)

• **Timely referral:** If a problem does not respond to primary care management, or is complex, refer to specialist palliative care for further advice.

The key points in managing symptoms are as follows:

- 1. Base the care components on the patient's idea of the quality of life.
- 2. Follow the five "A" s of chronic care "Assess, Advice, Agree, Assist, Arrange."
- 3. Correct the correctable contributory factors.
- 4. Involve the multidisciplinary team to address the care needs in all dimensions physiotherapist, psychologist, nutritionist, medical social worker, occupational therapist, yoga therapist etc. Use non-pharmacological as well as pharmacological treatment.
- 5. For any continuous pain, analgesia is better achieved with round-the-clock administration of analgesics rather than giving them SOS basis.
- 6. Keep the treatment regimen as simple as possible for the patient.
- 7. A formatted prescription with names of drugs, the reason for the use, dose and timings is more advisable than verbal advice.
- 8. Seek expert's advice in intractable situations.
- 9. Avoid false re-assurances yet maintain realistic hope.
- 10. Prioritize concerns from the patient's point of view.
- 11. Review and fine-tune care inputs.

#### General guidelines for all nurses.

- 1. Listen attentively. Be a good listener.
- 2. Do not consider the patient's problems insignificant.
- 3. Do not force your opinions/beliefs upon the patient.
- 4. Do not ignore the patient's queries.
- 5. Try not to give any false hopes.
- 6. Ensure confidentiality.

#### PAIN

Pain is an unpleasant feeling, such as a prick, tingle, sting, burn or ache. Pain is what the person says,"it hurts".

- **Definition:** "An unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage"- **International Association for the Study of Pain (IASP)** 
  - **Concept of pain**: Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors. Through their life experiences, individuals learn the concept of pain. Pain cannot be inferred solely from activity in sensory neurons.

#### **Assessment and Documentation of Pain**

Assessment and documentation of pain are essential for evaluating therapy efficacy, for a better understanding of the pain, for encouraging and supporting the patient and for future reference. A comprehensive pain assessment will allow for determining 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 and functions, assessment of the psychosocial factors and the current analgesic treatment, and the response to the same.

Assessment of a patient's pain requires a structured approach, good listening, and observation skills with constant re-evaluation. The assessment could get challenging if the patient experiences more than one type of pain. There are many approaches to assessing pain, and each professional will develop his/her approach to the history of pain. It is important to keep in mind an outline scheme for assessment with which you are confident.

#### **Assessing pain**

- Seek to establish a relationship with the patient.
- Encourage the patient to do most of the talking.
- Begin with a wide angle open question before on focusing and clarifying specifics.
- Watch the patient for clues regarding the pain.
- Avoid jumping to conclusions.

#### Pain assessment tools need to be valid, reliable and relevant.

#### **PQRST** of pain

A good understanding of the patient's pain forms the keystone of the development of a treatment plan. If not well controlled, pain can interfere with every aspect of the patient's daily life from their ability to carry out simple activities of daily living, such as washing and dressing, to their tolerance of other treatments.

Inadequate pain assessment is an important contributing factor to 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 the assessment of pain is that the clinician must accept the patient's self-report of pain. Using pain diagrams to document the pain ateach visit is a good practice.



Fig.3.2: PAIN DIAGRAM

#### Table 3.1: PQRST of Pain

R = Radiates
• Where does the pain radiate?
• Is it in one place?
• Does it go anywhere else?
• Did it start elsewhere and now
localized to one spot?
S = Severity
• On a scale of 0 to 10, with 0
being no pain and 10 being the
worst pain you can imagine,
how much does it hurt right
now?
• How much does it hurt at its
worst?
• How much does it hurt at its
Dest?
(I his is a difficult one as the ratingwill
differ from patient to patient.)
$T = Tim \rho$
• When did your pain start?
How offen does it occur?
<ul> <li>Has its intensity changed?</li> </ul>
<ul> <li>How long does it last?</li> </ul>

#### Pain Scales for Measurement of Intensity of Pain

Two types of Pain Scales are available.

- i. **Multidimensional:** 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.
- ii. **Unidimensional:** 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.
  - a) Numeric Rating Scale (NRS): 0 This is the most commonly used pain scale. The patient needs to rate the intensity of their pain on a scale of 0 to 10. Zero means no pain, while 10 stands for severe pain. This scale is commonly used for persons above the age of 10 years.



Fig.3.3: NUMERIC RATING SCALE

b) Visual Analog Scale: Visual Analog for Pain consists of a horizontal (or vertical) line. The left end of the line signifies no pain, which is depicted by a smiling face, while the right end signifies the worst possible pain with a frowning face. This visual depiction of pain levels helps patients communicate their pain intensity. As the intensity of pain in VAS is majorly depicted with images of facial expression, it can be used on a wide range of patients, including little children and elderly people who might not be accustomed to using other pain scales such as the Numerical Rating Pain Scale. It is much easier for any



Fig.3.4: VISUAL ANALOG SCALE

patient to express their perception of the intensity of their pain on VAS rather than converting it to a number as required in the Numerical Pain Scale. The patient can simply mark a spot on the scale that they feel represents their current state of pain.

c) Wong-Baker Faces Pain Scale (Observation scale for kids): The rating in Wong-Baker

pain scale is similar to the numerical rating but it combines pictures with the number for the rating of the pain. This scale can be used even for children as they can point to the face that depicts their intensity of pain.

Wong-Baker FACES Pain Rating Scale



Fig.3.5: WONG-BAKER FACES PAIN SCALE

# **Chronic pain**

Chronic pain refers to pain that persists for more than three to six months, beyond the expected healing time. Various underlying conditions, such as arthritis, fibromyalgia, nerve damage, or a pastinjury can cause it. Chronic pain can significantly impact an individual's physical, emotional, and social well-being, affecting their quality of life, sleep, mood, and ability to work and engage in activities.

# **Pathways of Chronic Pain**

Pain pathways comprise a complex sensory system, which is activated to provide protective responses to noxious stimuli.

- Nociceptors: Pain is caused by stimulation of free nerve endings called 'nociceptors'.
- **Peripheral sensitization:** Tissue injury as in trauma or disease like cancer, causes stimulation of free nerve endings in the skin and connective tissues like bone (somatic nociceptors) and viscera (visceral nociceptors). This results in the release of pain-producing substances like bradykinin, serotonin, histamine and prostaglandins. They sensitize the nociceptors to the effect of these substances, enhancing the pain.

- Central sensitization (spinal cord and brain levels): In the dorsal horn of the spinal cord, only a few specific interneurons take part in normal pain transmission. When these cells constantly are stimulated by long-standing continuous pain, the surrounding 'sleepy' receptors also get sensitized and increase the pain sensation. This is called central sensitization
- Recruitment: When pain is present for a prolonged period, the adjacent segments of the spinal cord also get stimulated, which is why patients complain of a wider area of pain than the actual anatomical area of the disease. Example: a patient with a cancer pancreas complains of chest and lower abdomen pain (although initially restricted to the T10/T11 dermatomes).
- Descending inhibitory pathway: This refers to inhibitory neurons (a built-in mechanism • inour nervous system) present in the dorsal horn cells, which block the transmission of pain impulses and are the major endogenous mechanism of pain inhibition. The descending pathways from the brain and thalamus stimulate these neurons. This helps modulate the degree of transmission at different levels of the pain pathway, and the final pain perception is a balance of these inputs.
- Connections within the brain: Pain impulses transmitted to the thalamus are relayed to • several areas of the cerebral cortex: the sensory areas of the parietal lobe, which allow localization and interpretation of the pain. The limbic system is involved in both the emotional and autonomic response to pain; the temporal lobe is involved in pain memory. The frontal lobe assesses the cognitive function, the significance of the pain based on emotional response and leads to pain behavior, which differs from person to person.

# **Pathophysiology of Chronic Pain**

Chronic pain is a complex condition influenced by various physiological, psychological, and social factors. It is defined as pain that persists for longer than three months and can be caused by various underlying conditions, including nerve damage, injury, inflammation, and disease.

The four main mechanisms involved in the physiology of pain transduction. are transmission, perception and modulation. These are the key processes involved in generating and perceiving painsignals in the body.

Transduction: Transduction is the process by which physical stimuli, such as heat, pressure, or injury, are converted into electrical signals by specialized nerve cells called nociceptors. Nociceptors are located throughout the body and are responsible for detecting potentially harmful stimuli.

Transmission: After a nociceptor is activated, it sends an electrical signal along nerve fibers to the spinal cord and the brain. The signal is transmitted through a series of synapses, or connections between nerve cells, which can Fig.3.6: PHYSIOLOGY OF PAIN amplify or dampen the signal. This process is known as transmission.



**Perception:** Perception is the conscious awareness of pain. It occurs when the pain signal reaches the brain and is interpreted as painful. The perception of pain is influenced by a variety of factors, including the intensity and duration of the pain signal, as well as the individual's emotional and cognitive state.

**Modulation:** Modulation is the process by which the intensity of pain signals is either amplified ordampened. Modulation can occur at several levels of the nervous system, including the spinal cord and brain. It involves the release of neurotransmitters, such as endorphins, which can inhibit the transmission of pain signals and reduce the perception of pain.

In summary, transduction is the conversion of physical stimuli into electrical signals by nociceptors, transmission is the process by which the pain signal is transmitted to the brain, perception is the conscious awareness of pain, and modulation is the process by which the intensity of pain signals iseither amplified or dampened

# **Classification of Pain**

Pain may be classified as 1) Nociceptive and 2) Neuropathic

#### **Nociceptive Pain**

This refers to pain resulting from the stimulation of peripheral nerves. Pain impulses enter the spinal cord through the dorsal horn and ascend to higher centers in the brain. Inhibitory impulses block transmission at the spinal cord- dorsal horn, preventing transmission of theimpulses.

#### **Neuropathic Pain**

Neuropathic pain is pain arising from damage to the peripheral or central nervous system. Clinical presentations include sensations such as burning or stabbing in areas of sensory loss. Central pain refers to neuropathic pain caused by damage within the central nervous system. There is usually an area of altered sensation incorporating the area of pain. A cerebrovascular accident or spinal cord damage may be associated with central pain.

Neuropathic pain could be of different forms, such as:

- Sympathetic-mediated pain is a relatively uncommon form of neuropathic pain due to sympathetic nerve injury. Essential features are pain (often with burning sensation) and sensory disorder related to a vascular as opposed to a neural distribution. Such a problem is also associated with reduced sweating and dry shiny skin.
- Hyperalgesia An increased response to painful stimuli.
- Allodynia A painful response to stimuli such as light touch that does not usually cause pain
- Phantom limb pain Phantom limb pain is a condition in which a person experiences pain or other sensations in a limb that is no longer present. This phenomenon is most commonly experienced by amputees, as it occur after a nerve injury or other trauma that results in the loss of a limb.



Fig3.7: DIAGRAMMATIC REPRESENTATION OF TYPES OF PAIN

# **Pain Management**

#### Introduction

Severe chronic pain, including 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. WHO analgesic ladder is a simple protocol for treating chronic pain.

#### **Management Principles:**

By the clock: Prescribe round- the- clock doses in contrast to SOS doses for effective pain relief. By the mouth: Start with oral immediate-release opioids, titrate to an effective dose before switching to sustained-release opioids.

By the ladder: Medications should be provided according to the severity of the pain.

# WHO LADDER FOR PAIN MANAGEMENT

The WHO Pain Ladder is a set of guidelines for the management of pain, developed by the World Health Organization (WHO) in 1986. It is a widely accepted approach for the treatment of pain in patients, particularly those with cancer.

The WHO Pain Ladder consists of three steps, each of which corresponds to a different level of pain severity:

Step 1: Non-opioid analgesics, such as Paracetamol and Non-Steroidal Anti-Inflammatory Drugs (NSAIDs), are used for the management of mild to moderate pain.

Step 2: If the pain is not adequately controlled with non-opioid analgesics, weak opioids such as Codeine or Tramadol can be added to the treatment regimen.

Step 3: If the pain is still not adequately controlled with weak opioids, strong opioids such as Morphine are added to the treatment regimen. Strong opioids are used for the management of severe pain.

The WHO Pain Ladder is designed to be flexible and can be adapted to the patient's individual needs. For example, a patient with moderate to severe pain may begin treatment with a weak opioid instead of a non-opioid analgesic, depending on their level of pain and individual circumstances.

Overall, the WHO Pain Ladder provides a framework for the management of pain that is widely used and has been shown to be effective in improving the quality of life for patients with pain.



#### WHO Analgesic Ladder

Once the patient is started on the analgesic ladder, they must be reviewed regularly to titrate the exact dose requirements and to assess for side effects, change in pain quality etc.

- STEP I: (MILD PAIN) Non-opioid (Paracetamol), NSAID (Diclofenac or Ibuprofen)
- STEP II: (MODERATE PAIN) Weak opioids like Codeine, Tramadol
- STEP III: (SEVERE PAIN) Strong Opioids like Morphine, Fentanyl, Buprenorphine

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

- NSAIDs exert an anti-inflammatory action by inhibiting prostaglandin synthesis. Commonly recommended NSAIDS are Ibuprofen, Diclofenac etc. Elderly patients or those with a history of peptic ulcers may be more at risk of getting side effects. A proton pump inhibitor such as Omeprazole has been shown to reduce this risk. Different NSAIDs have different reported relative risks. Ibuprofen has the safest side effect profile among traditional NSAIDs.
- Headache due to raised intracranial pressure may be semi-resistant to opioids. It is, therefore, better to try paracetamol. If necessary, these can be given rectally (paracetamol, naproxen or diclofenac) or subcutaneously (diclofenac or ketorolac).
- List of certain NSAIDs that can be used for pain relief:

Drug	Typical starting dose
Acetaminophen	650mg x 4hrly
Ibuprofen	200-800mg x 6hrly
Diclofenac Sodium	50-75mg x 8-12hrly
Naproxen	250-750mg x 12hrly
Piroxicam	10-20mg daily
Ketorolac	10 mg qid

 Table 3.2: NSAIDS

#### **Adverse effects of NSAIDs**

Continued use of NSAIDs may cause damage to the gastrointestinal, hepatic, renal system and interfere with platelet function. The symptoms may include nausea, heartburn, dyspepsia, gastrointestinal (GI) bleeding, and ulcers.

#### The risk of GI events with NSAIDs increases with

- Increasing dose of NSAIDs
- Increasing age
- NSAIDs used in combination with Aspirin
- NSAIDs /Aspirin taken with alcohol

# **OPOIDS**

These drugs are best given by the oral route and the dose is tailored to suit each individual's needs instead of trying to give the standard dose. The dose of Morphine varies from patient to patient. There is no set maximum dose or ceiling effect for morphine. An expert will administer high doses after appropriate titration against pain. Alternate routes of administration when oral administration is not possible for some reason are rectal, subcutaneous, intramuscular and intravenous.

The risk of addiction with the use of opioids is small and has been traditionally exaggerated. Morphine and other opioids should not be withheld for fear of addiction when the patient requires a stronger analgesic.

#### Commonly used opioids for pain relief:

Step II Weak Opioids (Oral)	Usual starting dose
Codeine phosphate	10 – 15 mg x 4hrly
Tramadol hydrochloride	50mg x 6hrly
Step III Strong Opioids (Oral)	
Morphine Sulphate (oral)	5 – 10 mg x 4hrly
	30 – 60 mg x 12hrly (sustained release)

# Table 3.3: OPIOIDS

#### **Oral Morphine**

Morphine administered by mouth or oral route is the choice for cancer pain. It is administered as tablets (i.e., 10 mg, 20 mg) or as aqueous solutions.

#### **Basics of Morphine use:**

- There is no standard dose or upper limit for chronic cancer pain. The correct dose is that which controls pain with minimal side effects.
- The dose is to be titrated for each patient.
- A laxative and anti-emetic for constipation and nausea/vomiting must always be given with morphine.

#### **Myths about Morphine**

- Used only for patients with cancer
- Use only when the end of life is near
- Can cause addiction/dependence
- Can cause respiratory depression
- Can't be used for children

#### Guidelines for starting a patient on Oral Morphine

- 1. Oral Morphine is indicated in patients with pain who do not respond to the optimized combined use of a non-opioid and a weak opioid.
- 2. If the patient takes two or more PRN doses in 24 hours, the regular dose should be increased by 30-50% every 2-3 days.
- 3. Prescribe stimulant laxatives. Adjust the dose as necessary. Constipation may be moredifficult to manage than pain.
- 4. Warn patients about the possibility of initial drowsiness.
- 5. For outpatients, write out the drug regimen in detail with time, name of drug and amount

tobe taken and arrange for follow-up.

- 6. Ordinary (normal/ immediate release) Morphine tablets or solution
  - Morphine is given q4h regularly 'by the clock' doses of an equal amount.
  - After 1-2 days, adjust the dose upwards if the patient still has pain or uses two ormore SOS doses per day.
  - Continue q4h regularly.
- 7. A double dose at bedtime obviates the need to wake the patient up for a 4 hourly dose in theearly morning.

#### Morphine - what to be careful about?

The following details should be kept in mind before starting a Morphine treatment regimen:

- Painkillers such as Morphine may be taken regularly if the cause of the pain has not been treated and cured. The effect of Morphine wanes in about four hours. Hence it has to be taken every four hours.
- A double dose may be taken at night in order to avoid waking up from sleep to take the medicine.
- Morphine does not cause acidity or heartburn, so it can be taken before or after food.
- Morphine induces constipation. Therefore, the medicine for constipation has to be taken along with Morphine on the doctor's direction.
- Morphine may induce vomiting initially in some patients. However, vomiting may not lastwith the normal Morphine course of a week or more.



Fig.3.9: PAIN RELIEF BY ORAL MORPHINE

It is advisable to take medicine to control vomiting while starting a Morphine regimen.

- If the patient is drowsy or delirious after taking Morphine, it could be due to an overdose. Stop the next dose and inform the doctor. The same is to be adopted if the vomiting is severe or if there is a urinary blockage.
- At no cost should the dosage recommended for one patient be followed for another patient.

#### Management of opioid overdose and side-effects

Patients should be warned of the possible side effects of Morphine, such as nausea and drowsiness that is usually temporary and often not a problem. If sleepiness continues for a few days, other possible causes, such as uremia, hypercalcemia or toxicity from other medications, should be excluded. Constipation is predictable, and most patients need prophylactic laxatives. If toxicity occurs, reduce the Morphine dose. The patient may need to miss several doses. Restart at a lower dose.

#### Side effects of opioids

- **Constipation**: Stepwise escalation of oral stimulant (Tablet Bisacodyl 10 mg HS increased to TDS) or if needed, an osmotic laxative (Syrup Lactulose) on opioid initiation.
- Nausea and vomiting: Usually self-limiting within 1 week. Prescribe Tablet Metoclopramide 10 mg TDS or Tablet Haloperidol 1.5-2.5 mg HS.
- **Drowsiness**: Initial drowsiness may be a sign of effective pain relief in a sleep-deprived patient. Stimulants such as Dextroamphetamine or Modafinil may be helpful if sedation

persists.

- **Delirium**: Assess for reversible causes like hypercalcemia and UTI. If no other cause is apparent, consider Haloperidol 2.5-5 mg HS/PO.
- **Myoclonus:** May respond to Benzodiazepines but may be a sign of opioid toxicity requiring hydration, opioid dose reduction or switching.
- **Pruritus and Sweating:** Try opioid rotation or 5HT3 antagonists (e.g. Ondansetron, Granisetron).

### **Morphine toxicity**

Common symptoms of Morphine toxicity are myoclonic jerks, over-drowsiness (difficult to arise), hallucinations and confusion.

Patients with renal impairment are at high risk of developing Morphine toxicity as the metabolites are excreted in the urine. If toxicity is observed, the drugs should be discontinued immediately. The patient may have to miss several doses for the toxic symptoms to disappear and should be started with the much lower dose and may require spacing 6th hourly, 8th hourly etc.

#### Signs of Overdose

- Drowsiness
- Delirium
- Myoclonus
- Respiratory depression (Very rare)

#### Use of Naloxone:

Respiratory depression due to oral Morphine is rare, although the incidence can increase whenMorphine is given intravenously.

#### Indications:

- Respiratory rate < 8 breaths/minute, difficult to arouse the patient and clinical evidence of cyanosis. OR
- Respiratory rate 10-12 breaths/ minute, difficult to arouse and oxygen saturation <90%

Dilute 0.4mg of Naloxone in 10 mL NS and administer 0.5 mL every 2 minutes until the normal respiratory rate is achieved. Once the normal respiratory rate is achieved, the patient should be constantly observed. This is because the half-life of naloxone is about 20 minutes, whereas the half-life of Morphine is about 4 hours. So the patient should be observed for more than 4 hours after the administration of naloxone. Once the effects of naloxone wear off, respiratory depression can again set in.

#### **Management of Neuropathic Pain**

The drugs used for Neuropathic Pain are considered as Adjuvant analgesics (Co-analgesics). It is a drug, which is not an analgesic in its prime function but can enhance pain control in combination with an analgesic. E.g., anti-emetics, anti-depressants, anti-convulsant, muscle relaxant, antispasmodic, antibiotics, anxiolytics and antacids.

# 1. Adjuvant drugs

Adjuvant drugs are used in addition to analgesics in pain relief. Adjuvants may belong to one of two categories –

- Drugs used to limit the side effects of analgesics
- Co-analgesics useful in certain types of pain

Along with drug therapy, it must be ensured that the patient's activities are analyzed, and those precipitating pain are avoided or reduced. Non-pharmacological measures like hot pads, relaxation, and music therapy may also be tried.

### 2. Tricyclic Antidepressants

The mechanism of analgesic action occurs principally by the facilitation of descending inhibitory pathways. E.g., Amitriptyline, Imipramine. Lower doses than the dose commonly required for depression will be effective in neuropathic pain. Other less sedating tricyclic antidepressants may be more useful for certain patients.

#### 3. Anticonvulsants

Carbamazepine tends to result in more side effects, mainly when combined with other drugs. Build up doses slowly to minimize adverse effects. Gabapentin is the only anticonvulsant licensed for treating neuropathic pain. Reported results with Gabapentin show that it is as effective as other anticonvulsants but may have fewer associated side effects and it is more expensive.

#### 4. Anesthetic Agents

Ketamine: An anesthetic agent causes dissociative anaesthesia and has shown to be analgesic at sub anaesthetic doses.

# 5. Other Drugs

**Topical Lignocaine** / **Bupivacaine**: It may be useful for superficial localized areas of pain such as fungating wounds for short periods. Prolonged use may lead to skin sensitization. Although the systemically absorbed dose will be small, care should be exercised with patients susceptible to cardiac problems.

**Capsaicin**: Capsaicin cream (0.75%) may be used for the pain from post herpetic neuralgia. Capsaicin is a derivative of chilli pepper and must be applied 4-5 times a day after wearing gloves.

# Nursing interventions for the management of pain.

- Assess pain characteristics using PQRST of Pain
- Assess for signs and symptoms associated with chronic pain such as fatigue, decreased appetite, weight loss, changes in body posture, sleep pattern disturbance, anxiety, irritability, restlessness, or depression.
- Assess the patient's perception of the effectiveness of methods used for pain relief in the past.
- Evaluate gender, cultural, societal and religious factors that may influence the patient's pain experience and response to pain relief.
- Assess the patient's expectations of pain relief.
- Assess the patient's attitudes toward pharmacological and non-pharmacological methods of pain management.
- For patients taking opioid analgesics, assess for side effects, dependency, and tolerance.
- Assess the patient's ability to accomplish activities of daily living, instrumental activities of daily living, and demands of daily living.
- Encourage the patient to keep a pain diary to help in identifying aggravating and relieving factors of chronic pain.
- Acknowledge and convey acceptance of the patient's pain experience.
- Provide the patient and family with information about chronic pain and options available forpain management.
- Assist the patient in making decisions about selecting a particular pain management strategy.
- Teach the patient and family about using non-pharmacological pain management strategies.
- Cold applications: Cold reduces pain, inflammation, and muscle spasticity by decreasing

the release of pain-inducing chemicals and slowing the conduction of pain impulses. This intervention requires no special equipment and can be cost-effective. Cold applications should last about 20 to 30 minutes.

- **Heat applications:** Heat reduces pain through improved blood flow to the area and reduction of pain reflexes. This is a cost-effective intervention that requires no special equipment. Heat applications should last no more than 20 minutes. Special attention needs to be given to prevent burns with this intervention.
- **Massage of the painful area:** Massage interrupts pain transmission, increases endorphin levels, and decreases tissue oedema. This intervention may require another person to provide the massage.
- **Progressive relaxation, imagery and music**: These centrally acting techniques for pain management work by reducing muscle tension and stress. The patient may feel an increased sense of control over his or her pain. Guided imagery can help the patient explore images about pain, pain relief, and healing.
- **Distraction**: Distraction is a temporary pain management strategy that works by increasing the pain threshold. It should be used for a short duration, usually less than 2 hours at a time. Prolonged use can add to fatigue and increased pain when the distraction is no longer present.
- Acupressure: Acupressure involves finger pressure applied to acupressure points on the body. Using the gate control theory, this technique works to interrupt pain transmission by "closing the gate". This approach requires training and practice.
- **Transcutaneous Electrical Nerve Stimulation (TENS):** TENS requires the application oftwo to four skin electrodes. Pain reduction occurs through a mild electrical current. The patient can regulate the intensity and frequency of the electrical stimulation.

#### Home care teaching

- Teach the patient and family how to give pain medications.
- Explain to the patient and caregiver about each analgesic's time of intake, duration, route, expected side effects and importance of PRN dose.
- Write out the instructions clearly on the medicine envelope.
- Encourage the patient to use complementary therapies like distraction, music and imagining peaceful scene, as much as possible.
- Explain the importance of drug compliance in pain management and discourage taking anyself-prescribed medications.

# Teach the family how to give oral Morphine.

- Teach the patient and family about the rectal route for Morphine administration in patients whocan't take it orally.
- Advise family on additional methods for pain control emotional support, physical method(touch, hot and cold application).
- Give adequate information on managing side effects of analgesics at home (e.g., constipation-
  - T. Dulcolax 5mg; dry mouth— ice chips, lemon pieces).
- Non-pharmacological interventions: A range of techniques exists to complement pharmacological approaches. Not all approaches will be appropriate for every patient. Positioning, reassurance, good communication, psychological support, joint mobility (passive & active), spiritual counselling, diversion therapy, art or music therapy, etc., are also useful.

# **DYSPNEA**

Dyspnea occurs in almost half of the patients referred for palliative care. It can be very frightening. It restricts activities. There is a loss of independence, frustration, anger and depression. Breathlessness at rest can cause anxiety and panic attacks. Patients often fear suffocating to death. Explanation and support are important.

Causes of Dyspnea	
Related to Cancer	Unrelated to cancer
• Cancer of the lungs, trachea or throat	• Asthma
• Cancer has spread to other parts of the	• Infections:Tuberculosis,
body	Pneumonia etc.
• Distension of the stomach due to either	Cardiac- related issues
cancer or fluid	Tobacco induced - lung diseases
• Anemia related to cancer	• Plural effusion or Pneumothorax

#### Table 3.4: CAUSES OF DYSPNEA

#### **Management:**

- 1. Some causes are reversible. e.g., wheezing due to tightening of airways. It can be made better with medicines given by the doctor. Check if the patient has been given any drugs or nebulizer earlier
- 2. Morphine is very helpful in decreasing breathlessness by acting on various centers in the brain.
- 3. Oxygen: It may help in a few cases where there is less oxygen in the blood, but in cases where the disease destroys the lungs, it may not help.

Possible cause	Management
Asthma	Bronchodilators, Corticosteroids, Physiotherapy
Pulmonary oedema	Diuretics, Morphine
Pneumonia	Antibiotics, Physiotherapy
Pneumothorax	Chest drainage, Oxygen

#### **Pharmacological Management**

#### Table 3.5: PHARMACOLOGICAL MANAGEMENT OF DYSPNEA

#### Non-Pharmacological Management

- Positioning Make the patient to sit in Fowler's position; avoid abdominal or chest compression and restrictive clothing
- Airflow encourage cool air flow over the face open window, electric fan, ceiling fan, handheld fan
- Distraction reading, relaxation, company, music, TV or radio
- Energy conservation / Functional pacing
- Encourage pacing and planning of exertion to tolerance.
- Controlled Breathing: Aim to reduce the rate of breathing (breath in, blow out)
- Encourage diaphragmatic ("use lower chest muscles") and pursed-lip breathing.
- Encourage relaxation of shoulders (e.g., take the weight off the shoulders by resting arms on support) and upper chest muscles on breathing
- Loose, comfortable clothes
- Wiping the face with a wet towel
- Massage of the shoulders may further assist relaxation and encourage diaphragmatic

breathing.

- Assess psychological factors: Listen to, understand, and address the patient's fears.
- Relaxation techniques used regularly can reduce long-term levels of anxiety and can be taught.
- Dyspnea is frightening to patients, families and staff. Reassurance and explanation are vital parts of the treatment, whatever the cause.
- Modifying lifestyle, breathing retraining and relaxation may be beneficial if instituted early.
- Consider referral to a physiotherapist or occupational therapist.
- A portable/table fan directed onto the face often eases dyspnea.
- Good oral care is important if there is persistent mouth breathing.
- Humidified oxygen may help acute dyspnea but should be used alongside other measures, and its use should be reviewed regularly. Respiratory physicians only should instigate long-term oxygen therapy for chronic respiratory illness.

# NAUSEA AND VOMITING

Nausea and vomiting can cause patients and their relatives great distress. Of the two, nausea causes the most prolonged misery. Many patients can tolerate one or two episodes of vomiting a day, while persistent nausea can be profoundly debilitating.

**Nausea** is an unpleasant wave-like sensation in the back of the throat epigastrium or throughout the abdomen that may or may not lead to vomiting.

**Vomiting** occurs when the contents of the stomach are forcibly and involuntarily expelled. It is generally preceded by nausea. In illnesses like cancer, problems in the food pipe and stomach/ bowel often result in severe vomiting and nausea. Chemotherapy medicines used in cancer also cause vomiting. Vomiting is found in bedridden patients due to certain other reasons too.

**Retching** is the movement of the diaphragm and abdominal muscles in a spasmodic, rhythmic manner. Usually, nausea is present, and the action results in vomiting. Retching is an attempt to vomit without expelling the contents.

#### **Common Causes of Nausea and Vomiting**

- Obstruction in the movement of food and water through the oesophagus,stomach and intestine due to cancer
- Medication-induced vomiting (chemotherapy, radiation)
- Some forms of cancer
- Brain tumor
- Certain medications like morphine etc.
- Infections
- Ascites
- Constipation
- Gastroparesis or slow stomach emptying
- A reaction to certain smells or odours
- Ulcers

#### **Assessment - Nausea and Vomiting**

Onset	When did the vomiting start? Is it related to food intake? What is the time interval between food intake and vomiting?
Amount	Number of episodes of vomiting What is the quantity of the vomitus? (Overall/ Each episode)
Colour	What is the colour of the vomitus? Is there any bloodstain in the vomitus?
Smell	Is there a foul smell to the vomitus?
Frequency	How many times in a day do you vomit?
Precipitating	Smell, food and other activities
factor	
Associated	Headache, abdominal pain, fever, heartburn,
symptom	abdominal distention, hiccups,
	constipation, loose stools, signs of dehydration
Sensorium	Conscious/semi-conscious/unconscious
	oriented/disoriented/calm/agitated/restless
Vestibular	Do you feel dizzy?
disturbances	
Drugs	What medications are you currently on?Recent chemotherapy or radiotherapy
If on NG tube	Amount, type and frequency of feeding
Examination	<ul><li>a) Per-Rectal digital examination if constipated</li><li>b) Blood pressure and Heart rate recording</li></ul>

#### Table 3.6: ASSESSMENT OF VOMITING

#### Consider the route of administration of medication as

- Persistent vomiting may reduce gastric emptying, resulting in decreased drug absorption.
- The parenteral route may reduce tablet burden, which may be a contributing factor to Nausea and Vomiting.
- For persistent nausea/vomiting, it is preferable to give subcutaneous infusion rather than bolus injections which are more apt for a single episode.
- Anti-emetics in suppository or tablet form can also be administered rectally.

#### Management of Nausea and Vomiting

- 1. Try to provide care to the patient in a well-ventilated room. Put on the fan if needed.
- 2. Avoid smells that cause nausea, e.g., the smell of cooking, phenol, Dettol, etc.
- 3. Keep a bowl for vomiting close by.
- 4. Give small portions of food at frequent intervals instead of big meals at one time.
- 5. Give liquid in small quantities (1/4 to ½ cup) at intervals of half an hour. Salted rice water (water drained out after cooking) or ORT (oral rehydration therapy) liquid or tender coconut water can be given.
- 6. Try to make the patient sit up while eating and let him not lie down immediately after food.
- 7. Give the patient the food that they prefer.
- 8. Make sure that the patient takes plenty of fluids.
- 9. Make sure that the medication prescribed for vomiting is taken in the proper dose at the appropriate time.
- 10. When the patient is feeling better, begin eating clear soups, mild foods, and liquids until all symptoms are gone for 12 to 48 hours.

- 11. Don't force the patient to eat too much at once. Stretching the stomach may worsen nausea and cause vomiting
- 12. Avoid milk, alcohol, caffeine, carbonated beverages, and most fruit juices. Milk may increase feelings of nausea.
- 13. Odour: avoid strong smells (e.g. food, infected/necrotic tumours, etc.), use deodorizers.
- 14. Dietary interventions:
  - small amounts of food more frequently
  - cold rather than hot food
  - avoid spicy, rich, fatty and very sweet food
  - salty food tends to be tolerated better, e.g. dry biscuits
  - small frequent drinks or sips of fluid
  - crushed ice cubes / frozen drinks such as Coke and fruit juice
  - Ginger is a useful antiemetic, in ginger tea or crystalline form
- 15. Good oral hygiene (especially after vomits)
- 16. Relaxation/distraction techniques
- 17. Position: sitting upright, head of the bed to relieve pressure on the abdomen
- 18. Relaxation therapy

#### **Signs of Dehydration**

<ul> <li>Increased thirst</li> <li>Dry mouth</li> <li>Swollen tongue</li> <li>Sunken eyes</li> <li>Too little urine</li> <li>Dark colour urine</li> <li>Confusion</li> <li>Skin that withdraws too slowly after being punched</li> <li>Weakness</li> <li>Dizziness</li> <li>Palpitations (feeling that the heart is jumping or pounding)</li> <li>Sluggishness</li> <li>Fainting</li> </ul>
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#### **Table 3.7: SIGNS OF DEHYDRATION**

#### **Home Care Education**

- Encourage small and frequent feeds.
- Encourage the patient to choose the menu.
- Explain to the patient and family about the signs and symptoms of dehydration and hyponatremia.
- Avoid taking high protein diet when the patient has nausea and vomiting.
- Make sure the patient is taking adequate salt –Normal salt intake 1.0-1.2 gm/day.
- Avoid sitting near the kitchen while cooking. This smell may aggravate nausea.
- Environmental modification eliminates strong smells and sights.
- Maintain good oral hygiene, especially after episodes of vomiting.
- Use complementary therapy to manage nausea and vomiting, e.g. Distraction.
- Rule out the cause- if it is constipation, consider laxatives or enemas as necessary.
- Educate the patient and family about taking the medication at the correct time. (e.g., T.Omeprazole on an empty stomach; T. Metoclopramide [Perinorm] 10mg half an hour before food).

# **CONSTIPATION**

Constipation occurs when bowel movements become difficult or less frequent. Constipation is a common problem in palliative care, affecting up to 90% of patients receiving palliative care. It can be caused by various factors, including decreased physical activity, decreased intake of fluids, dietary fiber, medications, and other underlying medical conditions.

### **Key Principles**

- "Prevention is better than cure".
- ALWAYS prescribe a laxative when commencing an opioid analgesic.
- Careful assessment of bowel patterns is crucial, e.g., the report of a bowel movement does not exclude constipation.
- In palliative care patients, constipation treatment differs from that in healthy active people.
- Even with inadequate oral intake, the bowel produces its own 'bulk', which can cause constipation.
- Remember, 'diarrhea' (spurious diarrhea) can overflow due to faecal paction (a detailed history can be helpful).

<ul> <li>General</li> <li>Lack of exercise</li> <li>Lack of physical activity</li> <li>Confusion, sedation</li> <li>Sense of guilt as the patient must depend on help for his basic needs.</li> <li>Lack of privacy</li> <li>Fatigue</li> <li>Stress</li> </ul>	<ul> <li>Disease-related</li> <li>Pain</li> <li>Certain health problems like Parkinson's disease, <u>hypothyroidism</u></li> <li><u>Fatigue</u></li> <li>Intestinal obstruction (Problems in the GI tract that compress or narrow your colon and rectum can cause constipation.)</li> <li>Spinal cord compression</li> <li>Dehydration</li> </ul>
<ul> <li>Nutritional</li> <li>Changes in the type of food.</li> <li>Decreased intake of food and water</li> <li>Lack of adequate fibre in food</li> <li>Low residue diet</li> </ul>	<ul> <li>Drug-induced</li> <li>Opioids (Morphine, Tramadol, Codeineetc.)</li> <li>Antidiarrheal</li> <li>Anti-depressants</li> </ul>

#### **Causes of Constipation**

# **Table 3.8: CAUSES OF CONSTIPATION**

Symptoms of Constipation	Assess for the following
<ul> <li>Few bowel movements</li> <li>Trouble having a bowel movement (straining)</li> <li>Hard or small stools</li> <li>A sense that everything didn't come out</li> <li>Swollen abdomen or abdominal pain</li> <li>Vomiting</li> </ul>	<ul> <li>How often does the patient have a bowelmovement?</li> <li>How long has the patient had symptoms?</li> <li>What does the stools look like and Whetherthe patient has blood in the stool?</li> <li>Eating habits</li> <li>Level of physical activity</li> <li>Type of medicines taken</li> </ul>

 Table 3.9: SYMPTOMS OF CONSTIPATION

#### Assessment of Constipation

Bowel pattern	How regular are your bowel patterns? (Before the onset of illness and now)
Dietary pattern	Amount of water consumed per day Inclusion of food rich in fibers
Consistency	Hard stools or soft stools
Duration	How long have you been having difficulty in bowel movements?When was the last time you passed stool to your satisfaction?
Associated symptoms	Vomiting, abdominal pain, Abdominal distention/abdominal fullness, Hiccups,Loose stools, visible peristalsis Increased bowel sounds
Drugs	What medications are you currently on? How frequently are you taking laxatives?
Perineal problems	Perianal ulcers/fissures, tumours, Haemorrhoids

#### Table 3.10: ASSESSMENT OF CONSTIPATION

#### Examination

- General examination: evidence of dehydration
- Abdominal examination: for prominent faucal masses/other masses
- Auscultate for bowel sounds
- Inspection of the anal area: look for haemorrhoids and anal fissure
- Rectal examination: soft or hard faeces, empty rectum
- If a stoma is present, then gently examine the stoma

#### Management

- 1. Correct any correctable causes.
- 2. With multiple ongoing risk factors, as they are in most cancer patients, suggest laxatives regularly versus SOS.
- 3. Titrate the dose of laxatives according to the response (stool frequency and consistency).
- 4. Stimulant laxatives are the first choice of laxatives for prevention and treatment.
- 5. Patients with irritable bowel syndrome may experience painful cramps with stimulant laxatives and often prefer osmotic laxatives such as lactulose or polyethylene glycol (PEG). However, lactulose can taste unpleasant and also cause bloating.
- 6. For patients with opioid-induced constipation, Methyl naltrexone may be helpful after a trial of first-line recommended stimulant laxatives and osmotic laxatives.
- 7. The rectal interventions are both undignified and unpleasant; however, their short onset of action can be extremely satisfying. Rectal interventions should be avoided when there is potential for severe infection (neutropenia), bleeding (thrombocytopenia), or rectal/analdisease.
- 8. If rectal measures are required (when bowels have not moved for more than three days). Generally, a stimulant suppository is tried first, then an enema as the next option.

#### **Prevention of constipation**

# Simple measures should be incorporated as part of the routine palliative care plan for all patients.

- Eating regular meals and making use of gastro colic reflex.
- Check the patients' perception of their bowel functions.
- Establish what is normal; Be mindful of bowel routine and comfort. Assess the patient's level of discomfort relating to constipation and its management. The aim of treatment is comfortable defecation and not increased stool frequency.
- Prophylaxis is better than treatment. Therapy should be regular and not intermittent, similar to the treatment of chronic pain. Always add a stimulant laxative with an opioid prescription.
- Mobility: Activity is the key stimulus to colonic peristalsis and defecation. Mobility should be encouraged as much as physical limitations permit.
- Regular toileting: keep a record of stool frequency.
- Maintain adequate oral fluid and fibre intake. Fibres must be avoided in severe constipation as they can precipitate colic pain.
- Provide privacy for going to the toilet, and maintain the same even if a bedpan is used.
- If the patient develops loose stool once or twice a day after starting the laxative, continue laxative at a lower dose than prescribed. If the patient passes a large volume of watery stool more than 4 times a day (always rule out spurious diarrhea), stop the laxative till stool normalizes, and give ORS in the interim period.
- Even after regular laxative use, 40 to 60% of terminally ill patients need additional rectal evacuation measures on a continuing basis.

#### Role of Nurses in Caring for a Patient with Constipation

- Assess the usual pattern of elimination; compare it with the present pattern. Include quantity, frequency, colour and quality of stool.
- Ensure privacy for the patient and provide bedside commode or bedpan, if required.
- Ensure the patient is taking medicines as per the prescription.
- Daily exercise may help to prevent and relieve constipation. Even bedridden patients should be given some light exercises according to their ability.
- Evaluate usual dietary habits, eating habits and liquid intake.
- Assess activity level.
- Evaluate current medication usage that may contribute to constipation.
- Maintenance of an adequate bowel protocol usually requires a prophylactic stool softener and stimulant.
- Encourage patients to drink plenty of fluids as tolerated while increasing their activity as appropriate.
- High fibre diet (e.g., raw fruits, fresh vegetables, whole grains) to be taken with adequate fluids.
- Consider enema and suppositories, if the patient can no longer tolerate oral medications.
- Digitally remove impacted stool if present, before giving suppositories and enema

#### **Overflow Diarrhea or Spurious Diarrhea**

Overflow diarrhea, also known as fecal impaction diarrhea, is a type of diarrhea that occurs when a hard mass of stool becomes impacted in the rectum and colon, preventing the normal passage of stool. As a result, liquid stool leaks around the impacted mass and causes diarrhea. Overflow diarrhea can be caused by a various factors, including chronic constipation, dehydration, poor bowel habits, and certain medications. It is more commonly seen in elderly patients, those with neurological disorders, and those who are bedridden or have limited mobility.

Treatment for overflow diarrhea involves removing the impacted stool, which can be done using laxatives, enemas, or manual evacuation. Once the impaction is removed, a bowel management plan should be established to prevent further constipation and the development ofoverflow diarrhea. This may include dietary changes, the use of stool softeners or laxatives, and establishing a regular toileting routine.

#### Instructions for home care patients:

- 1. Explain about laxative protocol necessary for the patient.
- 2. Explain to the patient that even though the patient is on a liquid diet, they are expected topass stools (at least a small volume).
- 3. Seek medical help when the patient has more than 2 to 3 days of constipation
- 4. Explain about spurious diarrhea.

# DIARRHOEA

Diarrhea is a common condition characterized by frequent (more than three times a day) loose, watery bowel movements.

Causes	Symptoms
<ul> <li>Unusual dietary habits</li> <li>Imbalance in laxative therapy</li> <li>Drugs: Antibiotics, Chemotherapy etc.</li> <li>Partial obstruction/ Fecal impaction</li> <li>Radiotherapy</li> <li>Rectal tumour/ RVF</li> <li>Faecal incontinence, loss of sphincter control</li> </ul>	<ul> <li>Urgent need to go to the toilet</li> <li>Watery stool</li> <li>Abdominal pain and cramping</li> <li>Change in colour of stool</li> <li>Mucus, pus, blood or fat in the stool</li> <li>Fatigue</li> <li>Nausea and vomiting</li> <li>Bloating and cramps</li> </ul>

# Table 3.11: CAUSES AND SYMPTOMS OF DIARRHEA

# ASSESSMENT OF DIARRHEA

Bowel pattern	• How regular are your bowel pattern?	
Dietary pattern	• Any recent change in food consumed?	
Consistency	Watery stool or mucoid stools	
Duration	• When did the diarrhea start?	
	<ul> <li>How long have you been having diarrhea?</li> </ul>	
Frequency	Number of episodes per day	
Associated symptom	• Vomiting	
	• Abdominal pain or cramps Abdominal distention, Fever	
	Signs of dehydration	
Drugs	• What medications are you currently on?	
	• How frequently are you taking laxatives?	
<b>General Examination</b>	Per-Rectal digital examination	
	Perianal skin condition	
	Blood pressure and Heart rate	

 Table 3.12: ASSESSMENT OF DIARRHEA

#### Role of nurses in caring for patients with Diarrhea (in palliative care setting)

- Assess the patient's normal bowel elimination pattern.
- Determine the cause of incontinence.
- Perform per rectal examination to rule out faecal impaction.
- Provide privacy for the patient.
- Ensure close proximity for the toilets/bedpan/commode.
- Ensure the patient has supportive clothing or pads.
- Assess the use of diapers and underpads.
- Assess perineal skin integrity.
- Correct any obvious factors related to the assessment.
- Notify the physician in a suspected case of bacterial infection.
- Educate the patient and family about cleaning the perineum carefully and gently after defecation.
- Instruct patient and family on any untoward signs and symptoms, including dizziness, excessive thirst, fever, etc.
- Provide support to the patient and family.
- Advice to eat small frequent bland meals. Low residue diet -potassium-rich.
- Avoid intake of hyperosmotic supplements.
- Increase fluids in the diet by at least 3 litres/day, which includes electrolyte drinks.
- After each evacuation, wash the perineal area with soap and water and dry them thoroughly.
- Treat any perineal irritation with moisture barrier ointment.
- Dispose pads, diapers, or collection devices as soon as possible.
- Administer drugs as per the prescription: Loperamide, Opioids, Codeine.
- Gradually reintroduce proteins and then fats to the diet as diarrhea resolves.

#### **Instructions for home care patients**

- 1. While cooking and storing food, the following rules can prevent diarrhea:
  - Wash hands before and after taking food
  - Always keep food that could spoil in the fridge
  - Use only boiled and cooled water.
  - Ensure that meat is cooked thoroughly
- 2. Always eat freshly prepared food (meat, fish, and shellfish).
- 3. Explain to the patient the signs and symptoms of dehydration.
- 4. Explain ORS preparation
- 5. Acknowledge the carer's burden and educate that sharing the work will reduce the burden
- 6. Explain the importance of maintaining skin integrity

#### NUTRITION AND HYDRATION

Maintaining and correcting nutrition is a significant problem in terminally ill patients, particularly when suffering from advanced malignant disease. Previous surgery, radiotherapy and chemotherapy worsen the problems. Hence intake of a balanced diet is necessary for mental and physical health. The patient and family must be educated about the importance of nutrition.

#### **General instructions**

- Diet must be planned according to the needs of the patient.
- Procedures to be done at least one hour before the meals.
- Serve the food in a good environment.
- In a bed-ridden patient, assemble everything near the patient and assist if needed.

- Give easily digestible food.
- Give time to the patient to eat the food.
- Talking to the patient while he/she is eating will make the patient feel good.
- Before and after food, give water for hand washing and oral care.
- Ensure adequate intake of fluids and dietary fibre.
- Eat as much as the patient wants and as frequently as he/she wants.
- Give nutritious food and dietary supplements as needed.
- Change food consistency as needed.
- Give nasogastric feeding when the patient is unable to accept oral feeding.
- Prevention and management of oral thrush, nausea, and constipation.

#### **Causes of deficient Nutrients**

- Anorexia
- Nausea and vomiting
- Obstruction in the alimentary tract and poor absorption
- Excessive loss of nutrients
- Cancer cachexia
- Adverse effects of the treatment
- Low socioeconomic status

#### In palliative patients:

- Assess the degree of nutritional deficiency.
- Decide the type, quality, route and administration of nutrients.
- Assess effects and side effects for further continuation.
- Consider the physical, psychological, social cultural and financial aspects of the patients and family.

#### **Routes of administration of Nutrients**

- Oral route
- Parenteral route or Central / Peripheral vein
- Oral route is the best, simplest, cheapest and most acceptable method.

Psychological factors like anxiety, depression and attitude of relatives are also contributing factors that affect the appetite of the patients which can be improved by

- Attractive presentation of food
- Pleasant environment
- Correct temperature and aroma of food
- Small frequent feeds
- Taste tolerance
- Effective communication
- Psychological support for both patient and family

#### Points to be kept in mind when patient is on naso-gastric feeding:

- Give the patient a Fowlers position or raise the chest with extra pillows.
- Prevent air entry inside the tube by pinching or folding the tube, opening the cap, and fixing thesyringe (20ml or 50ml).
- Aspirate the stomach contents and see whether the tube is in position.
- If the aspiration fluid is more than 50ml, skip the feed.
- Before and after the feed, give about 15- 20 ml of plain water.
- Give a total of 200 ml of prepared feed. (Total feed plus water not to exceed 250ml, according to the condition of the patient)
- Give the feed slowly without air entry.
- Ensure oral care every 4 hourly.
- Keep the patient in the same position for half an hour.
- Put the patient in side-lying position (to prevent aspiration)

# FATIGUE

Fatigue is a common symptom in palliative care patients and can significantly affect their quality of life. There are various reasons why fatigue can occur in palliative care patients, including the underlying disease, medication side effects and emotional distress. Therefore, managing fatiguerequires a multidisciplinary approach that includes medical, psychological, and social interventions. It is the self-recognized state in which an individual experiences an overwhelming sustained sense of exhaustion and decreased capacity for physical and mental work that is not relieved by rest. Fatigue is associated with a various physical and psychological conditions and not the same as tiredness which is temporary.

## Assessment

- Evaluate the patient's description of fatigue: severity, changes in severity over time, aggravating or alleviating factors.
- Using an appropriate quantitative scoring scale, 1 to 10, for example, can aid the patient informulating the amount of fatigue experienced.

## **Causes of fatigue**

- Previous physical illness
- Pain
- Psychological factors
- Side effects of medication
- Anaemia
- Disease progression
- Sleep disorders
- Imbalanced nutrition
- Extended responsibilities and demands at home or work

### Assessment

- Identifying the related factors to fatigue can benefit in recognizing potential causes andbuilding a collaborative plan of care.
- Assess the patient's ability to perform ADLs.
- Assess the patient's nutritional ingestion for adequate energy sources and metabolic demands.
- Evaluate the patient's outlook for fatigue relief, eagerness to participate in strategies toreduce fatigue, and level of family and social support.
- Review results of laboratory or diagnostic test:
  - Blood glucose
  - Hemoglobin/hematocrit
  - BUN
  - Oxygen saturation, resting and activity
- Changes in these physiological measures may be associated with other measurement data torecognize possible sources of the patient's fatigue.

- Observe physiological reaction to activities, such as any alterations in BP, respiratory rate, or heart rate.
- Assess the patient's ability for exercise and physical movement.
- Assess the patient's sleep patterns for quality, quantity, time taken to fall asleep and feeling upon waking up.
- Observe any alteration in thought processes or behavior after awakening.
- Assess the patient's routine medications and self medications.
- Assess the patient's emotional reaction to fatigue.

## **Management of Fatigue**

Managing fatigue requires a multidisciplinary approach that includes medical, psychological, and social interventions. Medical interventions may include the management of the underlying disease, adjusting medications, and managing symptoms that contribute to fatigue, such as pain, nausea, and breathlessness. In some cases, complementary therapies, such as massage or acupuncture, may alsobe used. Psychological interventions, such as counselling or cognitive-behavioral therapy, may help patients to manage emotional distress and improve their coping strategies. Social interventionsmay involve providing practical support, such as home care or transportation services, to reduce the physical and emotional burden on patients and their caregivers.

## Care of the patient with fatigue

- Restrict environmental stimuli, especially during planned times for rest and sleep.
- Encourage the patient to maintain a 24-hour fatigue or activity log for at least 1 week.
- Aid the patient with developing a schedule for daily activity and rest. Emphasize theimportance of frequent rest periods.
- Teach energy conservation methods. Collaborate with an occupational therapist as needed.
- Assist the patient with setting priorities for preferred activities and role responsibilities.
- Promote sufficient nutritional intake.
- Provide comforts such as judicious touch or massage and cool showers.
- Encourage verbalization of feelings about the impact of fatigue.
- Offer diversional activities that are soothing.
- Identify energy conservation methods such as sitting and dividing ADLs into convenientsegments.
- Set practical activity goals with the patient.
- Stay away from topics that annoy or disturb the patient.
- Aid the patient in developing habits to promote effective rest/sleep patterns.

# **POWERLESSNESS**

Powerlessness is a common experience for many patients receiving palliative care, as they may feel they have little control over their illness and the care they receive. This can be particularlychallenging for patients who are used to being independent and making their own decisions.

Powerlessness means that the person does not have the strength or resources to change a situation. **People with chronic conditions often have a long-term experience of powerlessness because they feel unable to change outcomes**. Managing real and perceived powerlessness is significant. Lack of control and the incapacity to act and change may dominate everyday life for persons with chronic illnesses. Accepting and acknowledging one's limitations due to chronic illness may result in a sense of helplessness.

Despite the limiting effects of chronic illness and feelings of powerlessness, individuals continue to exert power and control in areas of their lives through adaptation and accommodation to their evolving abilities. When power resources are significantly altered and affected, an individual

with chronic illness may experience feelings of powerlessness. To deal with this powerlessness, persons with chronic illness should direct their energy toward their intact power resources.

## The patient may experience Powerlessness as:

- A disruption of identity
- Loss of familiarity with bodily responses
- Loss of familiarity with emotional responses
- Loss of familiarity with social standing
- Loss of familiarity with one's environment

### Assessment

- Assess for feelings of apathy, hopelessness, and depression. These are the element ofpowerlessness.
- Determine the patient's power needs or need for control.
- Evaluate the patient's decision-making competence.
- Know situations/interactions that may add to the patient's sense of powerlessness.
- Appraise the impact of powerlessness on the patient's physical condition (e.g., appearance, oral intake, hygiene, sleep habits).
- Assess the role of illness plays in the patient's sense of powerlessness.
- Note if the patient needs information about illness, treatment plan, and procedures.
- Evaluate the results of the information given on the patient's feelings and behavior.

## Care of patients experiencing powerlessness

- Therapeutic communication encourage verbalization of feelings, thoughts, and concernsabout making decisions.
- Encourage the patient to identify strengths.
- Discuss with the patient concerning their care (e.g., treatment options, the convenience ofvisits, or time of ADLs).
- Encourage an increased responsibility for self-care.
- Help the patient re-examine negative perceptions of the situation.
- Eliminate the unpredictability of events by allowing adequate preparation for tests orprocedures.
- Give the patient control over their environment.
- Aid the patient in recognizing the importance of culture, religion, race, gender, and age ontheir sense of powerlessness.
- Support in planning and creating a timetable to manage increased responsibility in the future.
- Use of realistic short-term goals for resuming aspects of self-care and foster confidence inone's abilities.
- Avoid using coercive power when approaching the patient.
- Render positive feedback for making decisions and engaging in self-care.

# ANXIETY

Anxiety is a common issue for patients receiving palliative care. It can severely impair their quality of life and limit their mobility, social interaction, enjoyment, and sense of well-being. Anxiety can be caused by a various factors, including the patient's physical symptoms, the emotional impact of the illness, and uncertainty about the future. Anxiety disorders often co-exist

with depression in palliative care patients.

To help manage anxiety in palliative care, healthcare providers may use a combination of pharmacological and non-pharmacological interventions. Medications such as benzodiazepines or antidepressants may be used to reduce anxiety symptoms, while non-pharmacological interventionssuch as relaxation techniques, mindfulness meditation, and counselling may also be helpful. It's important to note that anxiety is a normal response to the stress and uncertainty of serious illness. It is important for healthcare providers to provide emotional support to these patients. They can alsowork with the patient and their family to develop a care plan that addresses the patient's anxiety and supports their overall well-being.

## Anxiety assessment

- Assess the signs and symptoms of anxiety like excessive worrying, increased motor tension, autonomic hyperactivity, and vigilance/ scanning.
- Assessment of the nature of anxiety, acute or chronic and whether part of another psychiatricsyndrome such as a depressive disorder.
- Assessment for any reversible factors such as pain or inappropriate medications. Stimulant drugs or excessive alcohol intake or withdrawal may exacerbate anxiety.
- Understand the unexplored worries. It is necessary to provide time and opportunity for patients to express their worries and concerns and for these concerns to be addressed honestly and clearly.

## **Management of Anxiety**

A non-pharmacological approach is recommended before initiating pharmacological therapy in managing palliative care patients.

## Lifestyle modifications:

## A) Exercise:

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

## **B)** Diet:

- The 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 balanced diet may be the only intervention required in somepatients with anxiety.

## C) Sleep:

- Sleep and anxiety are strongly linked. Anxiety can cause insomnia.
- Sleep hygiene education can promote good sleep, which includes avoiding frequent daytimenaps, late evening exercises, late heavy dinners, reducing intake of stimulants, reducing ambient noise and controlling other environmental factors that disturb sleep.
- Some drugs may also disturb sleep pattern (diuretics, steroids etc.,)
- Guided imagery is useful in preventing anxious thoughts that prevent sleep onset.

# **D)** Relaxation techniques:

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

# E) Mindfulness:

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

# F) Social activities and networking:

Social interactions and networking maintain connectedness. It is not only an essential social stimulusbut also improves synaptic connections. Purposeful social connections directed towards common goals offer engagement, focus and direction- e.g., Prayer gatherings, book clubs, social tasks, etc.

# Pharmacological management

Consider the following principles in the pharmacological management of anxiety disorders.

- SSRIs (Selective Serotonin Reuptake Inhibitors) are the first line of choice.
- When SSRIs fail, then move to other groups like Serotonin-Norepinephrine Reuptake Inhibitor (SNRIs), Tricyclic antidepressants (TCAs)
- Always monitor for hyponatremia and bleeding manifestations when SSRIs and SNRIs are used.
- Benzodiazepines have neuro-cognitive effects, can cause confusion, and dissociative phenomena, and increase the risk of falls. Avoid using benzodiazepines as much as possible. When used, limit use to 2 to 4 weeks.

# **Nursing Interventions for Anxiety**

Nursing interventions for Anxiety can apply to any individual with anxiety, regardless of etiologic and contributing factors.

- Recognize awareness of the patient's anxiety.
- Acknowledgement of the patient's feelings validates and communicates acceptance of thosefeelings.
- Use presence, touch (with permission), verbalization, and demeanor to remind patients that they are not alone and to encourage expression or clarification of needs, concerns, unknowns, and questions.
- Familiarize the patient with the environment and new experiences or people as needed.
- Interact with patients peacefully.
- Accept the patient's defenses; do not dare, argue, or debate.
- Communicate in simple language and brief statements.
- Reinforce the patient's reaction to or expression of pain, discomfort, or threats to wellbeing(e.g., talking, crying, walking, and other physical or nonverbal expressions).
- Lessen sensory stimuli by keeping a quiet and peaceful environment; keep "threatening" equipment out of sight.
- Allow the patient to talk about anxious feelings and examine anxiety-provoking situations if they are identifiable.
- If the situational response is rational, use empathy to encourage the patient to interpret the anxiety symptoms as normal.
- Recommend patients to keep a log of episodes of anxiety. Instruct the patient to describe

whatis experienced and the events leading up to and surrounding the event.

- Recognition and exploration of factors leading to or reducing anxious feelings are importantsteps in developing alternative responses. The patient may be unaware of the relationship between emotional concerns and anxiety.
- Encourage the patient to consider positive self-talk like "Anxiety won't kill me," "I can do this one step at a time," "Right now I need to breathe and stretch," "I don't have to be perfect." Cognitive therapies focus on changing behaviors and feelings by changing thoughts. Replacing negative self-statements with positive self-statements aids in reducing anxiety.
- Consider the patient's use of coping strategies that the patient has found effective in the past.
- Avoid unnecessary reassurance; this may increase undue worry.
- Reassurance is not helpful for the anxious individual.
- Assist the patient in developing new anxiety-reducing skills (e.g., relaxation, deep breathing, positive visualization, and reassuring self-statements).
- Intervene when possible to eliminate sources of anxiety.

# **SOCIAL ISOLATION**

Lack of social contacts and interaction with very few people can lead to social isolation. People usually face some loss at the end of life, whether that is their self-image, sense of control, relationships, or independence. This can mean that people are isolated from the things they love the most, including hobbies, interests, friends and what ultimately makes them feel like themselves. This is particularly relevant if someone has to change their living accommodation to allow for care. Loneliness is a sad feeling of isolation from others, usually accompanied by mental fatigue, bitterness, or despair. Loneliness is bad for physical and psychological health, while membership insocial groups acts as an umbrella in its appearance.

### **Causes of social isolation:**

- Loss of spouse
- Migration of children
- Empty nest Syndrome
- Financial insecurity
- Disability
- Social status
- Underlying psychiatric illnesses
- Depression

## **Approach to Social Isolation**

To address social isolation in palliative care, providers can take several approaches. One approach is to provide social support through hospice or palliative care services. These services mayinclude support groups, counseling, and spiritual care, all of which can help patients feel less isolatedand more connected to others.

Another approach is to involve family and friends in the patient's care. This can help to maintain important relationships and provide emotional support to the patient. Palliative care providers can work with patients and their families to identify ways to involve loved ones in the care process, such as attending medical appointments, helping with daily activities, or simply spending time together.

Technology can also be valuable in addressing social isolation in palliative care. Telemedicine and other communication tools can help patients stay connected with their care providers and loved ones, even if they cannot be together physically.

## **SPIRITUAL DISTRESS**

Spirituality is "a dynamic and intrinsic aspect of humanity through which persons seek ultimatemeaning, purpose and transcendence and experience relationship to self, family, community, society and nature. Spirituality is expressed through beliefs, values, traditions and practices." Spirituality is a very fluid concept. People tend to define it in very different ways. Some associate it with their concept of God, some do not.

Spiritual distress is an impaired ability to experience and integrate meaning and purpose through connectedness with self, others, art, music, literature, nature, and/or power greater than oneself. When people get sicker and approach the end of their life's journey, there is often a great deal of spiritual distress and suffering. Each person needs to come in to terms with their losses in their ownway. We are there to walk with them on that journey, not to tell them what to think, feel or believe. Therefore, we must not try to take the suffering away by trying to impose our own spiritual solutionsonto their spiritual struggles.

### **Assessment of Spiritual Distress**

- Assess history of religious affiliation.
- Assess spiritual beliefs.
- Assess the spiritual meaning of illness and death.
  - "Do you wonder regarding the meaning of your illness?"
  - "How does the current situation affect your relationship with God, your beliefs, orother sources of strength?"
  - "Do your illness and grief interfere with expressing your spiritual beliefs?"
- Assess whether patients need help with unfinished business.

## **Approach to spiritual Distress**

- Provide understanding and acceptance.
- Support crying by offering caring touch.
- Encourage verbalization of feelings of anger or loneliness.
- When the patient requests, arrange for priests, rituals, music, prayers, scriptures or images.
- If requested, sit with the patient who wishes to pray and arrange for a priest at the time ofdeath as per their request.
- Do not provide intellectual solutions for spiritual problems.

To address spiritual distress in palliative care, providers can take several approaches. One approachis to provide spiritual care, including counselling, prayer, and other forms of spiritual support. Palliative care providers can work with patients to identify their spiritual needs and preferences and develop a care plan that addresses them. Another approach involves chaplains or other spiritualleaders in the care team. These individuals can provide additional spiritual support and guidance and help patients connect with their faith communities and religious traditions.

# **IMPAIRED PHYSICAL MOBILITY**

Mobility is the ability to move the entire body freely and normally. It encompasses muscle strength, range of motion, and endurance capacity. Mobility is associated with physical movement, including both simple gross motor movements and more complex fine motor movements, along with associated coordination of those movements. With mobility, one can move functionally and efficiently with little to no restrictions or difficulty.

Physical mobility requires sufficient muscle strength and energy, adequate skeletal stability, joint function, and neuromuscular synchronization. Anything that disrupts this integrated process can lead to impaired mobility or immobility. Impaired physical mobility is a common issue for palliative care patients, as their illness or condition may limit their ability to move and perform daily activities. This can lead to decreased independence, increased dependence on others, and reduced quality of life.

Immobility and its complications have been shown to have the potential to cause physical disability and emotional suffering for patients, as well as to increase healthcare costs for facilities and communities. A comprehensive understanding of the concept of mobility is critical to providingoptimal patient care. By incorporating appropriate assessment skills, early mobilization efforts, andproper prevention strategies, the nurse can help patients recover their former degree of mobility andflexibility in support of an optimal quality of life.

## Causes of impaired mobility or inability to move freely

- Muscle imbalance
- Muscle weakness
- Tightness
- Improper alignment and posture
- An injury that is currently in rehabilitation or was not fully or properly rehabilitated.

## Signs and Symptoms

- Inability to move purposefully within the physical environment, including bed. mobility,transfers, and ambulation.
- Inability to perform the action as instructed.
- Limited ROM.
- Reluctance to attempt movement.

## Some diseases which may cause impaired physical mobility are

- Alzheimer's Disease and Dementia
- Amputation
- Burn Injury
- Cerebral Palsy
- Cerebrovascular Accident
- Congenital Hip Dysplasia
- Fracture
- Guillain-Barre Syndrome
- Hemophilia
- Kawasaki Disease
- Laminectomy
- Osteoporosis
- Parkinson's Disease
- Rheumatoid Arthritis
- Scoliosis
- Spinal Cord Injury

### Assessment

Impaired physical mobility represents a complex healthcare problem involving many differenthealthcare team members.

- Assess for impediments to mobility.
- Assess the strength to perform ROM to all joints.

- Assess input and output records and nutritional patterns.
- Monitor nutritional needs as they relate to immobility.
- Evaluate the need for assistive devices.
- Assess the presence or degree of exercise-related pain and changes in joint mobility.
- Assess the safety of the environment.
- Assess the emotional response to the disability or limitation.
- Consider the need for home assistance (e.g., visiting home care team).
- Assess the patient's or caregiver's understanding of immobility and its implications.
- Note for progressing thrombophlebitis (e.g., calf pain, Homan's sign, redness, localizedswelling, a rise in temperature).
- Check for skin integrity for signs of redness and tissue ischemia (especially over ears, shoulders, elbows, sacrum, hips, heels, ankles, and toes).

# Nursing Interventions for impaired physical mobility

- Assist patient for muscle exercises as able or when allowed out of bed; execute abdominal exercises and knee bends; hop on foot; stand on toes.
- Present a safe environment: bed rails up, bed in a down position, and essential items closeby.
- Establish measures to prevent skin breakdown and thrombophlebitis from prolonged immobility.
- Clean, dry, and moisturize the skin as necessary.
- Use anti-embolic stockings or sequential compression devices if appropriate.
- Use pressure-relieving devices as indicated (air/water/gel mattress). This is to prevent skin breakdown, and the compression devices promote an increased venous return to prevent venous stasis and possible thrombophlebitis in the legs. It may also decrease pressure on skin or tissues that can damage circulation, potentiating tissue ischemia or breakdown and decubitus formation risk.
- Turn and position the patient every 2 hours or as needed. Position changes optimize circulation to all tissues and relieve pressure.
- Execute passive or active assistive ROM exercises to all extremities to enhance increased venous return, prevent stiffness, and maintain muscle strength and stamina. It also avoids contracture deformation, which can build up quickly and could hinder prosthesis usage.
- Promote and facilitate early ambulation when possible. Aid with each initial change:dangling legs, sitting in the chair, ambulation.
- Show the use of mobility devices, such as trapeze, crutches, or walkers. These devices can compensate for impaired function and enhance the level of activity. Such aids are to promote safety, enhance mobility, avoid falls, and conserve energy.
- Help with transfer methods by using reasonable assistance of persons or devices when transferring patients to bed, chair, or stretcher.
- Let the patient accomplish tasks at their own pace. Do not hurry the patient. Encourage independent activity as able and safe.
- Give positive reinforcement during the activity. Patients may be unwilling to move or initiate new activities because of fear of falling.
- Consider energy-saving techniques. Rest periods are essential to conserving energy. Provide the patient with rest periods in between activities.
- Give medications as appropriate. Antispasmodic medications may reduce muscle spasms or spasticity that interfere with mobility, analgesics may reduce the pain that impedes movement.
- Help the patient in accepting limitations. Let the patient understand and accept their limitations and abilities. On the other hand, assistance must be balanced to prevent the patient from being unnecessarily dependent.
- Encourage resistance-training exercises using light weights when suitable. Strength training

and other forms of exercise are believed to be effective in maintaining independentliving status and reducing the risk of falling in older adults.

- Help the patient develop sitting balance and standing balance. This helps out in retraining neuronal pathways and motor responses.
- Keep limbs in functional alignment with one or more of the following: pillows, sandbags, wedges, or prefabricated splints. Maintain feet in a dorsiflexed position. This avoidsfoot drop and too much plantar flexion or tightness.
- Encourage coughing and deep-breathing exercises. Use suction as necessary. Make use of an incentive spirometer.
- Present suggestions for nutritional intake for adequate energy resources and metabolic requirements. Correct nutrition is necessary to keep a sufficient energy level.
- Encourage a diet high in fibre and a liquid intake of 2000 to 3000 ml per day unless contraindicated. Liquids maximize hydration status and avoid hardening of stool. It also decreases the risk of skin irritation or breakdown.
- A sedentary lifestyle contributes to constipation. Set up a bowel program (e.g., adequate fluid, food high in bulk, physical activity, stool softeners, laxatives) as needed. Note bowelactivity levels.
- Offer diversional activities. Observe emotional or behavioral reactions to immobility. Forced immobility may heighten restlessness and irritability. Diversional activity helps in refocusing attention and promotes coping with limitations.
- Explain to the patient the need to call for help, such as a call bell and special sensitive call light.
- Set goals with the patient or significant other for cooperation in activities or exercise and position changes.
- Reinforce principles of progressive exercise, emphasizing that joints are to be exercised to the point of pain, not beyond. "No pain, no gain" is not always true! Pain occurs because ofjoint or muscle injury.
- Teach the patient or family to maintain a home atmosphere hazard-free and safe to prevent injury related to falls and help the patient maintain a desired level of functional independenceand reduce fatigue with activity.
- Explain the progressive activity to the patient. This may help to increase self-confidence and reduce frustration.

## **Patient teaching**

- Adherence to recommended prevention and treatment strategies can significantly affect whether the patient will regain mobility or develop immobility-related complications.
- Educate patients and their families regarding the risks of impaired mobility and the importance of maintaining the highest level of physical activity possible.
- Discuss the importance of turning and repositioning to maintain skin integrity. Explain that passive and active range-of-motion exercises will help the patient maintain joint flexibility, muscle strength, and muscle mass.
- Discuss fall prevention techniques. For example, teach patients to change positions slowly to avoid orthostatic hypotension.
- Stress the importance of optimal nutrition in healing; the patient and family should understand that meals high in protein and nutrients benefit healing. Also, inform patients about the importance of adequate fluid intake to help prevent both urinary tract infections and constipation.
- The psychological impact due to impaired mobility and immobility can be devastating. Provide the patient and family with information about support groups and community resources as appropriate for any identified physiological, psychosocial, spiritual, and financial needs.

# **SELF CARE DEFICIT**

Self-care refers to those activities an individual performs independently throughout life to promote and maintain personal well-being. Activities of daily living or ADLs are defined as the task we regularly do such as feeding ourselves, bathing, dressing, grooming, work, homemaking and leisure. However, there are some that might have difficulties in performing self-care.

Self-care deficit is the inability of an individual to perform self-care. The deficit may be the effect of temporary limitations, such as those one might experience while recovering from surgery, or theresult of gradual deterioration that erodes the individual's ability or willingness to perform the activities required to care for themselves.

Assisting in activities of daily living is the skill required in nursing. The nurse coordinates services to maximize the patient's independence and ensure that the environment the patient lives in is safe and supportive of their special needs.

### Assessment

- Assess the patient's strength to accomplish ADLs efficiently and cautiously on a daily basis. The patient may need help with some self-care measures related to eating, bathing, grooming, dressing, toileting, bladder and bowel management, transfer, ambulation, and/orstair climbing.
- Determine the specific cause of each deficit (e.g., visual problems, weakness, cognitive impairment).
- Consider the patient's need for assistive devices.
- Recognize choice for food, personal care items, and other things.
- Evaluate gag reflex prior to initial oral feeding.
- Verify the need for home health care after discharge.
- Monitor impulsive behavior or actions indicative of altered judgment.

## **Nursing Interventions**

- Establish short-term goals with the patient to help them set realistic goals to reduce frustration.
- Guide the patient in accepting the needed amount of dependence.
- Present positive reinforcement for all activities attempted, note partial achievements.
- Render supervision for each activity until the patient exhibits the skill effectively and is secured in independent care. Regularly re-evaluate to ensure that the patient is keeping the skill level and remains safe in the environment.
- Implement measures to promote independence but intervene when the patient cannot function.
- Boost maximum independence.
- Apply regular routines and allow adequate time for the patient to complete the task.

## Feeding

- Allow the patients to feed themselves as soon as possible (using the unaffected hand, if appropriate). Assist with the set up as needed. The dominant hand may also be affected if there is upper extremity involvement.
- Ensure the patient wears dentures, hearing aid and eyeglasses if required.
- Place the patient in a comfortable position for feeding.
- Provide the patient with proper utensils (e.g., wide-grip utensils, rocking knife, plate guard, drinking straw) to aid in self-feeding.

- Ensure that the consistency of diet is suitable based on the patient's ability to chew and swallow. Thickened semisolid foods such as pudding and hot cereal are most easily swallowed and less likely to be aspirated.
- If vision is affected, guide the patient about the placement of food on the plate. After Cerebro vascular accident (CVA), patients may have unilateral neglect and may ignore half of the plate.
- Provide an appropriate setting for feeding where the patient has supportive assistance.

## **Dressing/Grooming**

- Provide privacy during dressing.
- Use appropriate assistive devices for dressing as assessed by the nurse and occupational therapist.
- Suggest elastic shoelaces or Velcro closures on shoes.
- Give frequent encouragement and aid while dressing as needed. Assistance can reduce energy expenditure and frustration.
- Dressing requires energy. Utilise a wheelchair or stationary chair. A chair that provides more support for the body than sitting on the side of the bed saves energy when dressing.
- Establish regular activities so the patient is rested before any activity.
- Consider the use of clothing one size larger.
- Recommend a front-opening brassiere and half-slips in females.

### **Transferring/Ambulation**

- For moderate assistance, the caregiver places arms beneath both patient's armpits with the caregiver's hands on the patient's back.
- For patients needing maximal assistance, use a gait belt.
- Raise the bed to a height that allows the patient's feet to be flat on the floor.
- Grasp the gait belt with both arms and pull the patient forward.
- Place a knee against the patient's weak knee (if applicable) and encourage the patient to put weight on the strong side during the transfer.
- Encourage the patient to use their arms to assist, as able, and to place them on the caregiver's forearms.
- This method maximizes patient support while protecting the care provider from injury.
- Aid with ambulation, direct use ambulation devices such as canes, walkers, and crutches.
- Stand on the patient's weak side.
- If using a cane, place the cane in the patient's strong hand and ensure proper foot-cane sequence.
- These methods promote patient safety and aid with balance and support.

### Toileting

- Assess previous and present patterns for toileting, introduce a toileting routine. The efficacyof the bowel or bladder program will be improved if the patient's natural and personal patterns are considered.
- Assess patient's ability to verbalize necessitate to void and/or capacity to use the urinal and bedpan. If suitable, bring the patient to the bathroom regularly or intermittently for voiding.
- Provide privacy while the patient is toileting. Lack of privacy may reduce the patient's ability to empty the bowel and bladder.
- Give a bedpan or put the patient on the toilet every 1 to 1½ hours throughout the day and three times throughout the night. Time intervals can be prolonged as the patient starts to verbalize the need to toilet on demand. This eradicates incontinence.
- Give suppositories and stool softeners.

- Observe the patient closely for loss of balance or fall. Maintain commode and toilet tissue close to the bedside for night time utilization. Patients may hurry to the toilet or commode throughout the night due to fear of soiling themselves and may fall.
- Keep the call light within reach and teach the patient to call promptly. This allows staff members ample time to help transfer to the commode or toilet.
- Aid patients in eliminating or changing unnecessary clothing. Clothing that is not easy to get n and out may compromise a patient's capability to be continent.
- Consider utilization of commode or toilet as early as possible. Patients are more successful in emptying their bowel and bladder when sitting on commode. Several patients find it unfeasible using a bedpan.
- Recognize prior bowel habits and restore normal regimen. Increase bulk in diet, fluid intake, and activity. It supports the progression of retraining program and helps avoid constipation and impaction.
- Educate family and significant others to promote autonomy and intervene if the patient becomes tired, incapable of carrying out tasks. This displays caring and concern but does nothinder with patient's efforts to attain autonomy.
- Inform family members to allow the patient to perform self-care measures as much as possible.
- Note: This may be very hard and discouraging for the significant other or caregiver, depending on the extent of the disability and the time needed for the patient to accomplish the activity.
- Promote independence but intervene when the patient cannot carry out self-care activities. A suitable level of assistive care can avoid harm with activities without causing disappointment.
- Entertain patient input in the planning schedule. Patient's worth of life is improved when wishes or likes are taken into consideration in daily activities.
- Consider or use energy-conservation techniques. This saves energy, decreases fatigue, and improves the patient's capability to execute tasks.

## **DELIRIUM**

Delirium is a disturbance in consciousness and cognition that can result in confusion, disorientation, and difficulty with memory, attention, and thinking. Delirium is a state of mental confusion that develops quickly, usually fluctuates in intensity, and results in reduced awareness of and responsiveness to the environment. It may manifest as disorientation, incoherence and memory disturbance. Delirium is a common issue for patients receiving palliative care, especially in the advanced stages of their illness.

## Causes

- Infection: Pneumonia, sepsis
- Metabolic encephalopathy: organ failure, paraneoplastic syndromes
- Endocrine: Hyper/hypothyroidism, Cushing syndrome
- Drug withdrawal: Alcohol, narcotics, hallucinogens
- Immunologic: Systemic lupus erythematosus (SLE), vasculitis
- Nutritional deficiencies
- Drugs

## **Approach to Delirium**

- Monitor and record consciousness level, temperature, pain scores, pressure sores, and neurological and rectal examination findings.
- Administer drugs as per the prescription.

- Stop any offending treatment.
- Correct metabolic abnormalities.
- Quiet room, dim lights, calendar, clock.
- Family support.
- Treat reversible causes (dehydration, hypercalcemia etc.)

## **Nursing Management**

- Identify the cause, including the precipitating, aggravating, and palliating factors.
- Provide pharmacological and non-pharmacological management.
- Providing a safe environment and reassuring the patient that we keep them safe.
- Communicate with the patient and family calmly, with a non-judgmental attitude, and use simple terms.
- Give only one choice or one decision to prevent agitation.
- Pay active listening when they express their feelings during delirium and support the patientand family.
- Get the complete history of the recent changes after the health team visit and investigationor medication.
- Keep the patient hydrated and maintain the nutritional status.
- Maintain and encourage the family members to maintain normal urinary and bowel patterns (constipation and urine retention can cause delirium).
- To avoid anxiety and fear, minimize unnecessary stimuli. Encourage the use of assistive devices.
- Maintaining proper position technique encourages active and passive exercise.
- Effectively manage the pain because it can exacerbate delirium.
- Administer medications, such as antipsychotics, sedatives, and analgesics, as prescribed, following safe medication administration practices.
- Monitor for adverse reactions, including increased confusion.
- Reorient the patient continuously about the time, place, and person. Keep the clock, calendar, orientation board on the wall facing the patient.
- Call the patient by name and give them a mirror to help him get oriented by himself.
- Maintain a consistent schedule and stable environment.
- Keep the patient's belongings in the same location to decrease confusion.
- Provide music, magazines, and games with which he was familiar earlier.
- Encourage the family to talk about the past event step by step.
- Suggest to the family the importance of following sleep hygiene for these patients.
- Try to care for the patient with the same team members and avoid unnecessary equipment inside the patient room.
- Managing a patient with delirium in the home is extremely stressful for the family. Assessthe family members' coping abilities and provide the necessary support.
- An interdisciplinary team approach is needed to manage these patients.
- Palliative sedation is preferred at the end of life in reducing or eliminating symptoms as a primary goal and supporting the family or other caregivers during this critical period.

# **CARE GIVER ROLE STRAIN**

Palliative care patients are said to be the most vulnerable group in society. The life-limiting illness affects not only the patient but also their entire family. Providing palliative care is often an exercise of treating the part, if not the whole, family of the patient. In addition to causing distress to the patient, it puts financial, personal, social, and health stress on family members. Family members close to the patient may play the role of caregiver.

Caregiver strain is a common issue in palliative care, as caregivers often experience physical, emotional, and social stress associated with caring for a loved one who is terminally ill. The excessive stress and demands on caregivers can lead to care giver role strain which is experienced when a caregiver feels overwhelmed and cannot perform their role to the best of their ability. Caregiver role strain symptoms are very similar to everyday include stress and feeling overwhelmed, being pessimistic, displaying an inability to relax, and having widespread aches and pains (among many other things). Feeling of stress and anxiety accompany it. FIG.3.10: CARE GIVER Caregiver strain often goes



unrecognized. In the hustle and bustle of a busy life, it may not be detected until the family caregiver suffers a health crisis of their own.

## Interventions

There are steps you can advise a family caregiver to decrease the caregiver strain. Advise them to

- Utilize in-home care services: Respite care to take a personal break, adult day care, counselling and rehabilitation services on a routine basis to assist with the family member's care.
- Seek financial help: If finances are an issue, approach an ASHA worker, who may advise you on available resources to help bridge the gap. She may also refer to Village Health, Sanitation and Nutrition Committee/Jan Arogya Samiti/ Mahila Arogya Samiti/ Resident Welfare Association who will ensure the availability of benefits from various governments and non-governmental programs/ schemes to the eligible patients/ caregivers.
- Ask for and accept help. Many family caregivers feel obligated to provide all the care and support their loved one needs. It is challenging to do and can put both at risk for illness or injury. Make a list of the task others could help with and ask other family members to help with those specific chores.
- Set reasonable expectations for self and others. Care rendered may differ from person to person and should not be criticized. Let the care given be good enough to keep the patient from risk for injury.
- Talk with the physician/nurse and make sure they know about the family caregiver. They may want to take extra steps to protect the caregiver's health, such as monitoring the blood pressure at home or prescribing a vitamin supplement.
- Encourage self-care. This may be the most difficult one for family caregivers to accept, but making time to take a brisk walk five days a week and eat a good diet can help them to stay healthy.
- Education and support: Providing caregivers with education about the patient's illness, trajectory, and symptom management can help them better understand and cope with the situation. Caregivers may also benefit from support groups, counselling, and respite care to help them manage their emotional and physical needs.
- Care planning: Developing a care plan that outlines the patient's needs, the roles and responsibilities of the caregiver and other healthcare team members can help to reduce the

caregiver's burden and promote effective communication.

• **Providing support to the caregiver:** Recognizing and addressing the caregiver's symptoms and needs, such as pain, anxiety, and depression, can help to promote their well-being and improve their ability to provide care.

Overall, addressing caregiver strain in palliative care requires a multi-disciplinary approach that considers the needs of both the patient and the caregiver. By providing education, support, and practical assistance, healthcare professionals can help to reduce caregiver burden and promote the well-being of both the patient and their caregiver.

# Conclusion

Palliative care focuses on preventing and relieving suffering and providing palliative care patients with the best possible quality of life. These patients typically experience multiple symptoms, the most common of which are pain, depression, anxiety, fatigue, breathlessness, insomnia, nausea, constipation, diarrhea, and anorexia. Symptom management helps the person feel more comfortable, improving physical well-being, functionality, and quality of life.

# Activity for Unit 3

## 1. Multiple-choice questions

- 1. Pain associated with nerve damage is known as:
  - a. Nociceptive pain
  - b. Neuropathic pain
  - c. Psychopathic pain
  - d. Referred pain
- 2. The best intervention to prevent opioid-induced constipation is:
  - a. Give Fibre-rich diet
  - b. Give Laxative along with opioids
  - c. Reduced dosage of the opioid if a patient develops constipation
  - d. Give more than 2-3 litters of fluids
- 3. Non-pharmacological interventions for breathlessness include the following, EXCEPT:
  - a. Try controlled breathing techniques.
  - b. Turn the fan on towards the patient.
  - c. Be with the patient and reassure him that you are with him.
  - d. Give nebulization.

## 2. Group Activity/ Case Discussion

Objective: To reinforce the symptom assessment and appropriate intervention.

Activity instruction: Students will be divided into groups and given case scenarios. Encourage themto discuss assessment and management; the group leader will be asked to present to the class.

- a) **Case 1.** A 60-year-old man with a history of metastatic colonic carcinoma has been admitted tothe hospital. He has intolerable pain and has been complaining of constipation for two days. **Discussion Points:** 
  - 1. How to assess his pain?
  - 2. Discuss the other concerns this patient will be facing.
  - 3. How can we manage this patient's constipation?
- b) **Case II:** A 48-year-old woman presents with nausea and vomiting. She has a history of breast cancer with widespread bone metastases. She is vomiting large amounts (mostly undigested food) several times. She is intermittently nauseated and feels better for some time after vomiting. She was started on Tab. Morphine q4h for pain three days back.

### **Discussion Points:**

- 1. What are the common causes of nausea and vomiting in palliative care patients?
- 2. Discuss the likely cause of nausea and vomiting in this patient.
- 3. What is the standard drug given before giving Morphine to prevent vomiting?
- c) **Case III**: A 54-year-old man was diagnosed with advanced cancer left lung 18 months back. He has been experiencing a rapid deterioration in his health. He is currently unable to leave the house

due to breathlessness; he struggles with self-care and generally feels very low due to hisincapacity.

## **Discussion Points**

- 1. What assessment will you carry out on this patient?
- 2. Discuss the non-pharmacological management of breathlessness.
- 3. Explain the nursing care to be provided for this patient.
- d) **Case IV:** Mr. Suresh is a 65-year-old male diagnosed with advanced pancreatic cancer. He was admitted to a hospice for palliative care due to the progression of the disease and the inability to tolerate chemotherapy. Mr. Suresh had a history of hypertension, diabetes, and chronic kidney disease, for which he was receiving medications. He had a poor appetite and weight loss and was experiencing severe pain in the abdomen, affecting his quality of life.

## **Discussion Points**

- 1. Discuss some issues that may affect his Quality of Life.
- 2. As a palliative care nurse, explain how you manage Mr. Suresh.
- 3. Discuss health education to be given to Mr. Suresh during his discharge.

## Essays

- 1. Enumerate the common symptoms experienced by patients receiving palliative care. Discuss the nursing management of any one symptom.
- 2. Describe the recommended approach to managing pain in palliative care patients
- 3. What are the common causes of constipation in palliative care patients, and how can they be managed effectively?
- 4. Discuss nursing care for a patient with delirium.
- 5. Discuss the problems of Caregiver and Role of a nurse in addressing these issues.

## Written Assignments

- 1. Write a care plan for any patient with chronic pain, cancer pain, or cancer-related breathlessness.
- 2. Write a care plan for a patient with delirium/ chronic constipation.
- 3. Prepare AV Aids on home teaching for a patient with breathlessness/vomiting.

# Unit 4

# NURSING PROCEDURES

## Introduction

Palliative care nursing involves many procedures to comfort and support patients with serious illnesses or conditions. The role of palliative care nurses is to provide compassionate, patient-centered care that meets the unique needs of each patient and family. In this module, we will discuss some of the common nursing issues and their care in palliative care.

## **Wound Care**

Effective wound management and symptom control are essential in promoting comfort and quality of life for patients in the palliative care setting. In palliative care, wound care can be challenging due to the complex nature of the wounds and the patient's underlying medical conditions. The goal of wound care in palliative care is to provide comfort and symptom management, rather than cure or complete healing.

Here are some considerations for managing healing and non-healing wounds:

- **Healing wounds:** In palliative care, some wounds may have the potential to heal, and efforts should be made to facilitate healing as much as possible. This involves identifying the underlying cause of the wound, such as pressure or friction, and addressing it. This may include repositioning the patient regularly, using appropriate support surfaces, and treating any infections that may be present. Wound dressings are used to promote healing and reduce the risk of infection.
- Non-healing wounds: Some wounds may not heal completely due to the nature of the wound or the patient's underlying medical condition. In these cases, the goal of wound care is to manage symptoms and prevent complications such as infection or further tissue damage. This may involve using dressings to manage exudate and odour, controlling pain, and maintaining skin integrity.

## 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 holistic approach improves patients' quality of life 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 the adjacent tissues, and when a nerve is infiltrated, the patient suffers from excruciating neuropathic pain.
- **Bleeding:** It is a problem with malignant ulcers. Because of the neovascularisation of a malignant tumour, these ulcers tend to bleed and are often difficult to manage.
- **Exudate:** Malignant wounds produce excessive exudates due to the vascular permeability of the tumour. Not all exudates are of infective origin—the presence of purulent exudate points to infection.
- **Malodour:** The cause of malodour is multifactorial. Infections, necrotic tissue and heavy exudates also produce malodour. The presence of dead, necrotic tissues in the wounds makes it suitable for bacteria to colonise, resulting in further tissue destruction and the production foul smelling exudates. Malodour causes severe distress to patients and their families. It affects the appetite, interferes with sexual function, restricts social interaction, and leads to isolation.

- **Pruritis:** Pruritis in malignant fungating wounds is caused by stretching of the skin. This excessive stretching causes nerve irritation. The dryness of the skin adds to the problem.
- **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, flies lay their eggs producing maggots. Maggots, though eat only the dead tissue, their movement causes pain, and the site 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 in itself causes frustration to the patient and families. Daily dressing is painful, cost and the time lost in the dressing adds to this frustration. In patients with malignant wounds when the patients notice that the wound is only increasing in size even after repeated dressing, they get more frustrated and disheartened.
- Anger: Frustration leads to anger and resentment. Treatment failure, physical problems associated with the wound, and family and social isolation results in anger.
- Anxiety: Anticipating pain is one of the important causes of anxiety. Families choosing not to reveal the diagnosis to the patient is a very common problem in our settings. This often results in collusion. For a patient not knowing the diagnosis and having an ulcer that is taking a long time to heal is distressing. This is another important source of anxiety.
- **Depression:** Patients with chronic wounds suffer from depression. Hopelessness, family and social isolation play an important role in leading the patient into depression.
- **Body-image issues:** When the ulcer is in a place that is visible to others (Face and oral cavity) sense of shame usually isolates the patients. Some even isolate themselves from seeking medical treatment.
- **Sexual problem:** Chronic pain due to chronic ulcers decreases the libido. Foul smell, discharge, family conflicts and spousal dissatisfaction exponentially worsen this.

## Social problems

- **Isolation within the family:** A patient with a malignant fungating wound is usually confined to a dark corner of the house. Children don't visit that room, someone from the family enters the room with food and water and do dressing. Families often do this to protect the patient without any malicious intent. But this completely isolates the patient from the family and patient 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 on 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.
- **Reduced mobility:** Wounds that affect mobility can limit a person's ability to participate in activities they enjoy or are necessary for daily life, such as work or caring for children.
- Stigma and discrimination: Wounds that are visible or associated with certain conditions, such as HIV or substance abuse, can lead to stigma and discrimination from others.
- **Caregiver burden:** Wounds that require routine care can cause caregiver burden, especially if the caregiver is a family member who must balance caregiving responsibilities with other obligations.
- **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 is required to visit the hospital every time for dressing. Loss of wages, loss of time and other healthcare expenditures push the family into poverty.

# **Spiritual problems**

- Loss of meaning and purpose: Wounds can lead to loss of meaning and purpose, particularly if the patient is unable to engage in activities that give meaning to his/her life.
- **Questioning faith and beliefs**: Wounds can cause patients to question their faith or spiritual beliefs, particularly if they struggle to find meaning in their suffering or feel that their faith has failed to provide comfort or healing.
- Anger and resentment: Wounds can cause anger and resentment towards a higher power, particularly if the patients feels that they have been unfairly afflicted or feel abandoned by their spiritual beliefs.
- **Guilt and shame:** Wounds can cause feelings of guilt and shame, particularly if the person feels that their wound is a punishment for past actions or if they feel that their wound has made them unworthy of spiritual grace.
- Loss of community: Wounds can lead to a loss of community, particularly if the patients are unable to participate in religious or spiritual practices that were previously important to them.
- 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 causes fear and frustration among patients. In some proportion of patients, the suffering makes them more spiritually active and engaging.

# **Common Wounds in Palliative Care**

Several common types of wounds may occur in the palliative care setting, including:

- 1. **Pressure ulcers:** Pressure ulcers, also known as bedsores, are a common type of wound that can develop when a person is immobile or spends a lot of time in one position. They typically occur over bony areas and can be difficult to heal.
- 2. **Malignant wounds:** Malignant wounds are a complication of advanced cancer and can be difficult to manage. They may be painful, have a foul odor, and require specialised wound care.
- 3. Venous ulcers: Venous ulcers are a type of wound that occurs when there is damage to the veins in the legs, which can lead to swelling, inflammation, and open sores. They are often slow to heal and may require compression therapy.
- 4. Arterial ulcers: Arterial ulcers are a type of wound that occurs when there is damage to the arteries in the legs, which can lead to reduced blood flow and tissue damage. They are often painful and slow to heal.
- 5. Diabetic ulcers are a common type of wound that can occur in people with diabetes. They typically develop on the feet or lower legs and are caused by a combination of factors, including poor circulation, nerve damage, and high blood sugar levels.

# **Care of Wounds in Palliative Care**

In palliative care, wound care is an important aspect of patient comfort and quality of life. The care of wounds in palliative care focuses on promoting healing and preventing infection while providing pain relief and symptom management. Here are some key aspects of wound care in palliative care:

- **Cleaning the wound**: The wound should be cleaned with a gentle solution, such as sterile saline, to remove debris and bacteria. This should be done using sterile gloves and a sterile technique.
- **Dressing the wound:** The wound should be covered with an appropriate dressing, which may depend on the type and severity of the wound. The dressing should be changed regularly to prevent infection and promote healing.
- **Managing pain:** Wound care can be painful, so pain management is important to palliative care. This may include medications, such as opioids or nonsteroidal anti-inflammatory drugs (NSAIDs), as well as non-pharmacologic pain management techniques, such as massage or heat therapy.
- **Preventing infection:** Infection can be a serious complication of wounds, especially in palliative care, where the immune system may be compromised. Measures to prevent infection may include hand hygiene, wearing gloves and other personal protective equipment, and using sterile techniques when cleaning and dressing the wound.
- Addressing psychosocial concerns: Wound care can be emotionally and psychologically challenging for patients and their families. Palliative care providers should address any concerns or fears related to the wound care process and provide emotional support as needed.

# **PRESSURE ULCER**

Pressure ulcers are a common problem in palliative care. Patients nearing the end of life may be bedridden or unable to move around, increasing their risk of developing pressure ulcers. In palliative care, the focus is on providing comfort and relieving suffering, so preventing and managing pressure ulcers is an important part of patient care.

# **Causes of pressure Ulcer**

## **Extrinsic Factors**

- **Pressure:** Prolonged pressure on the skin and underlying tissues is the primary cause of pressure ulcers. This can occur when a person remains in one position for an extended period, such as when they are bedridden or in a wheelchair.
- Friction: Friction occurs when the skin rubs against a surface, such as bedding or clothing, causing skin damage. Friction can also occur when the skin is dragged across a surface, such as during transfers or repositioning.
- Shear: Shear occurs when the skin is pulled in one direction while the underlying tissues are pulled in another. This can occur when a person slides down in bed or when the head of the bed is elevated too high.

## **Intrinsic Factors**

- Age: Older adults have thinner skin, less natural cushioning over bones and poor nutrition
- Lack of pain perception: e.g., Spinal cord injuries
- **Malnutrition:** Both obese and thin patients are at risk of developing pressure sores. But in thin patients, the progression stages of pressure sore are faster due to the lack of subcutaneous fat.
- Urinary or faecal incontinence: Moist skin can break down easily. Bacteria from faecal matter can cause infections
- **Co-morbidities:** Diseases conditions affecting circulation (diabetes mellitus, vascular diseases) / Smoking (Nicotine impairs circulation and reduces the amount of oxygen in the blood)
- Decreased mental awareness by disease (CVA), trauma or medications.

## Potential sites of pressure injury

Some potential sites for pressure ulcers include:

- 1. **Bony prominences:** Areas where bones are close to the skin, such as the hips, tailbone, heels, and ankles, are common sites for pressure ulcers
- 2. Skin folds: Skin folds, such as those around the groin or under the breasts, can be vulnerable to pressure ulcers due to friction and moisture.
- 3. **Back of the head:** Patients who spend a lot of time lying on their backs may develop pressure ulcers on the back of their heads.
- 4. Shoulders and shoulder blades: Patients who spend a lot of time lying on their sides may develop pressure ulcers on their shoulders and shoulder blades.
- 5. Elbows, knees, and other joints: Joints subjected to prolonged pressure or friction, such as the elbows and knees, can be vulnerable to pressure ulcers.
- 6. **Ears and nose:** Patients who spend a lot of time lying on their side may develop pressure ulcers on their ears or nose.



Fig. 4.1: POTENTIAL SITES OF PRESSURE ULCER

7. **Feet and toes:** Patients who are unable to move or change position may develop pressure ulcers on their feet and toes.

# **Stages of Pressure Ulcer**

Pressure ulcers, also known as bedsores, are classified into four stages, according to the depth and severity of the wound:

- **Stage 1:** This is the earliest stage of pressure ulcer, where the skin is intact but is discolored, usually appearing as a reddened or darker area. The area may be painful or tender to the touch, and the skin may feel warm or cool compared to the surrounding tissue.
- **Stage 2:** At this stage, the skin is no longer intact and may have a shallow open wound or blister. The ulcer appears as a partial-thickness skin loss that may be red, pink, or a blister, with a shiny or dry wound bed. The area may be painful, and there may be some swelling.
- Stage 3: In this stage, the ulcer extends deeper into the skin and subcutaneous tissue, forming a fullthickness wound. The ulcer appears as a deep crater-like wound, with visible fat and may have a foul odor. There may be significant tissue damage, including necrosis or slough, and the patient may experience significant pain.
- **Stage 4:** This is the most severe stage of pressure ulcer, where the wound extends even deeper into the muscle and bone. The ulcer appears as a full-thickness wound, with extensive tissue damage and loss, exposing bone, tendons, or muscles. The patient may experience significant pain, and there may be a risk of infection.







Fig.4.2: STAGES OF PRESSURE ULCER

# **Management of Pressure Ulcer**

Here are some key nursing considerations for managing pressure ulcers in palliative care:

- **Prevention:** The first key principle is preventing pressure ulcer from developing. This involves regularly repositioning patients, ensuring proper support surfaces (such as pressure-reducing mattresses), and keeping their skin clean and dry.
- Assessment: Regular skin assessments can help identify pressure ulcers early and manage them appropriately. The assessment should include identifying the stage of the ulcer, measuring its size, and determining the level of pain or discomfort the patient is experiencing.
- **Pain management:** Pressure ulcers can be painful, especially as they progress. Appropriate pain management, including using analgesics and other pain-relieving interventions, is important to ensure that the patient is comfortable.
- **Wound care:** Wound care should be tailored to the individual patient and their specific needs. This may involve debridement, cleaning the wound, applying dressings, and managing exudate.
- **Psychosocial support:** Patients with pressure ulcers may experience embarrassment, shame, or social isolation. Providing psychosocial support can help address these feelings and improve the patient's quality of life.

It's important to remember that pressure ulcers can significantly impact a patient's quality of life, and effective management requires a holistic, patient-centred approach. Working closely with a multidisciplinary team, including wound care specialists, nurses, and other healthcare providers, can help ensure that the patient receives comprehensive and effective care.

# MALIGNANT WOUNDS

Malignant Wounds/ Fungating wounds are very distressing for patients with advanced cancer. The term 'fungating' refers to a malignant process of both ulcerating and proliferative nature. Lesions with a predominantly proliferative growth pattern may develop into a nodular 'fungus' or 'cauliflower shaped lesion, whereas a lesion that is ulcerating will produce a wound with a craterlike appearance. These fungating wounds may develop during the last few months of life.

Malignant wounds are a common complication of some advanced cancer and can be challenging to manage in palliative care. They are caused by infiltration of the skin by a local tumour and recurrent or metastatic spread from a primary tumour. Sometimes a chronic wound may undergo malignant transformation to produce a fungating wound.

The goal of wound care in palliative care is to optimise patient comfort and quality of life rather than to achieve complete wound healing.

### **Assessment of Wound**

Assessing a chronic wound involves a comprehensive evaluation of the wound and the surrounding skin to determine its size, location, depth, and any underlying causes. Here are some common steps involved in the assessment of a chronic wound:

- Wound history: A detailed history of the wound is important, including when the wound first appeared, its location, size, and duration. The history should also include any previous treatments or interventions.
- Wound characteristics: It's important to document the appearance of the wound, Fig.4.3: MALIGNANT BREAST CANCER WOUND including its color, depth, shape, and



presence of drainage or odor. Photographs and wound measurements can also be helpful in tracking changes over time.

- **Wound bed:** The type and condition of the wound-bed can provide important information about wound healing potential. The wound-bed should be assessed for tissue type (e.g., granulation, slough, eschar), moisture level, and presence of infection.
- Peri wound area: The skin around the wound should be assessed for signs of inflammation, infection, or damage. The peri-wound area should also be assessed for the presence of edema, hyperkeratosis, or other skin conditions that may affect wound healing.
- Pain assessment: The patient's pain level should be assessed using a validated pain scale. The location, duration, and intensity of pain should be documented, as well as any factors that exacerbate or alleviate the pain.
- Health status: A comprehensive health assessment should be conducted, including a review of medical history, current medications, and any comorbid conditions that may affect wound healing.
- Nutritional status: Nutritional status can impact wound healing. It's important to assess for malnutrition, including low serum albumin levels, and other factors that may impact nutrition status such as dietary intake and food insecurity.

• **Psychosocial, social and spiritual factors:** Chronic wounds can significantly impact a patient's quality of life.

# **Management of Wound**

Here are some key principles to keep in mind when managing malignant wounds in palliative care:

- 1. **Pain management:** Pain control is a crucial aspect of palliative wound care. Pain can be managed with various medications, including opioids and non-opioids, and non-pharmacological interventions, such as positioning, relaxation techniques, and distraction.
- Give an extra dose of pain medication half an hour before dressing.
- Previous dressing materials should be soaked and removed to minimise pain during dressing. Another method is the use of non-sticky dressings.
- Maintaining the wound in a moist environment will reduce dressing adherence and protect exposed



Fig.4.4: MALIGNANT WOUND

nerve endings. Pain can be kept in check using a dressing material requiring less frequent changes.

- Irrigation of the wound with saline rather than cleaning with a gauze swab will reduce pain.
- Complementary therapies, such as relaxation, distraction or visualisation, can play an important part in pain management.
- 2. **Wound Care:** The goals of wound management in palliative care are to minimise pain, odor, and exudate, and to promote healing. Wound dressings can be used to cover and protect the wound, and topical agents such as hydrogels, antimicrobials, and odor-absorbing agents can be used to manage symptoms. Consider anticancer treatment- RT, CT, debriding surgery in the case of cancers

# A) Maggots

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

- Wound should be covered with dressing all the time and changed daily.
- If maggots are present, apply or flush plain turpentine oil in the wound with a syringe. Protect the eye, nose and ear with a pad and instruct the patient not to swallow if turpentine is spilled accidentally in the oral cavity, as there will be irritation. Wait for 10 minutes after the application of turpentine. Remove maggots with the help of forceps.



Fig.4.5: MAGGOTS IN WOUND

• Maggots come out from the hidden pockets of tissue when there is a lack of oxygen supply and irritation from turpentine vapour. Therefore, turpentine flushing must be repeated for 3-4 days to remove all maggots. When completely removed, teach the carer the correct way of wound cleaning and dressing.

## **B)** Malodour

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

- Daily bath before dressing
- Cleaning with normal saline
- Mop the wound gently with gauze. Apply Metrogyl
- Application of Metrogyl powder to the wound.
- If the wound is dry and painful, apply Metrogyl powder (crushed Metrogyl tablets) mixed with Lignocaine jelly.
- Change wound dressing at least twice a day until malodour settles.

# C) Discharge

• Cancer wounds often produce excessive amounts of discharge, which can be difficult to manage. Keep changing the dressings once soaked.

# D) Bleeding:

- Wound bleeding is common in cancer wounds.
- Always mask the bleeding with dark-colored clothes.
- If dressings are not soaked while changing, bleeding may occur.
- Bleeding occurs when cleaning roughly.
- Using non-adherent dressings that maintain a moist environment
- Clean the wound by irrigation rather than swabbing will reduce trauma and bleeding.
- Gentle removal of dressing after soaking with saline or water is a good practice.

## E) Infection:

- Thorough bath before dressing reduce malodour, infection and washes off exudates.
- The wound should be cleaned with normal saline or preferably under running water.
- Antibiotics may be used to manage infections, and regular wound assessments should be performed to monitor for signs of infection.

## 3. Patient's comfort

- Use dressings that will be most comfortable to the patient and cost-effective.
- Used cotton saris or soft cloth can be made into gauze pieces and gamgee pads.
- Coloured pads have the advantage of masking the colour of blood or exudate from wounds.

## 4. Nutrition

Good nutrition is essential for wound healing, and patients with malignant wounds may require additional nutritional support. Dietary counselling and supplements may be recommended to help ensure that patients are receiving adequate nutrients.

## 5. Psychosocial support

Malignant wounds can significantly impact a patient's quality of life, and psychosocial support can be beneficial in managing the emotional and psychological aspects of wound care. Counselling, support groups, and other forms of psychosocial support may be helpful for patients and their families.

In summary, managing malignant wounds in palliative care requires a comprehensive approach that addresses wound care's physical, emotional, and psychosocial aspects. The focus should be maximising patient comfort and quality of life rather than achieving complete wound healing.

#### **Health Education and Home Care Management**

We can help the patient and the carers by teaching them the proper procedure to be used while caring for their loved ones. Explain to the carer that fungating wound is non-healing and, although it will be present lifelong, the symptoms can be controlled. Provide the carer with support, counselling and practical demonstration of preparing dressing material at home.

### Carers can use the following protocol for home-based sterilisation technique:

Preparation of saline for cleaning and dressing: Add one pinch of salt in one glass of water or two teaspoons of salt in 1 litre of water. Boil the solution for half an hour. Keep this water in a clean closed container, and it can be used as per need

**Preparation of Dressing Material:** Simple dressing material can be prepared at home. Family members can be advised to preserve dark-coloured clothes to be used to clean bleeding wounds. An old cotton cloth that has been washed well with soap and water and dried in sunlight can be used. The clean cotton cloth should be cut into small pieces, steamed for half an hour, and stored in a clean airtight container.

The following advice also should be given:

- Hand should be washed before and after dressing. ٠
- Waste materials should be properly disposed.
- Regular follow up with healthcare worker is critical.

# **COLOSTOMY CARE**

Though the words 'ostomy' and 'stoma' are used interchangeably, they have different meanings. Ostomy is a surgery to create an opening (Stoma) from inside to outside. A stoma is an opening that connects a body cavity to the outside environment. Ostomies, based on their purpose, are classified into two types.

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

**Colostomy:** A colostomy involves creating an opening in the abdomen and pulling through a portion of the colon. This allows stool to pass directly from the colon, bypassing the diseased or damaged part. The consistency and frequency of the stoma discharge depend on the colostomy type performed. Depending on the site, there are four main types of colostomies: ascending, transverse, descending, and sigmoid.

1. Ascending colostomy: This procedure is performed on the ascending colon, on the right side of the abdomen. This discharge is often irritating to the skin around the Fig.4.6: TYPES OF COLOSTOMY



stoma (peristomal skin). The stool that passes from this type is liquid and is rich in digestive enzymes.

- 2. **Transverse colostomy:** This procedure is performed on the transverse colon across the abdomen. Discharge from this type is usually liquid to semi-formed in consistency and is less irritating to peristomal skin.
- 3. **Descending colostomy:** This is performed on the descending colon, on the left side of the abdomen. The stool is semi formed to formed in consistency because most of the water has been absorbed as it moves through the ascending and transverse sections of the colon.
- 4. **Sigmoid colostomy:** This procedure is performed in the sigmoid colon, on the lower left side of the abdomen. The stool has a normal, formed consistency.

## Stoma management

The management of stoma patients in palliative care nursing involves *three* principles:

- i. Assessment of patient's general condition, application of knowledge of the different types of stoma in planning and evaluating the outcome
- ii. Management of the stoma and stomal appliances
- iii. Providing physical and psychological care

## **Common Issues**

- **Stoma colour:** Normal colour is deep pink to deep red and should be checked regularly. If the stoma appears blue or purple, it could be a sign of inadequate blood flow to the stoma, known as ischemia. If the stoma appears black or brown, it may be a sign of necrosis or tissue death. Necrosis can be caused by a variety of factors, including ischemia, trauma to the stoma, or infection. This is a serious condition that requires immediate medical attention.
- **Stoma bleeding:** It is usually seen at the time of cleaning or changing the bag. Apply local pressure for 10 minutes and use sucralfate powder to control bleeding. Other causes of bleeding may be:
  - **Trauma:** Any injury to the stoma site can cause bleeding. This can be due to accidentally hitting or scratching the stoma.
  - **Infection:** Infection at the stoma site can cause bleeding. It is essential to keep the stoma site clean.
  - Medications: Some medications, such as blood thinners, can increase the risk of bleeding
- **Stoma herniation:** Stoma herniation is a condition where the intestine protrudes through the stoma site, the opening in the abdominal wall created during the surgery for stool to pass through. Stoma herniation can cause discomfort, and pain, and can even lead to blockages in the intestine. When the patient lies in the supine position, it usually reduces. But in some cases, the hernia does not reduce and should be reported immediately.
- Stoma prolapse occurs when the stoma protrudes outward from the abdominal wall. It can be caused by weak muscles in the abdominal wall or excessive strain on the stoma site. Stoma prolapse can also cause discomfort, pain, and can even lead to blockages in the intestine, and distension and needs surgical intervention. A prolapse of 1.5 cm of stoma outside the skin level is acceptable in a colostomy. A prolapse of 5 cm needs surgical intervention.
- Stoma retraction: stoma withdraws inside: If there is no interference with bowel movement, intervention is not needed. Otherwise, surgical correction is advised. Special attention is to be given to peristomal skin.

## **Colostomy pouch**

A colostomy pouch is a medical device that is used to collect waste products from the colon after a colostomy surgery. The pouch is attached to the stoma site, which is the opening in the abdominal wall created during the surgery.

## **Types of Colostomy pouch**

There are two main types of colostomy pouches: one-piece and two-piece pouches.

- One-piece pouches are made of a single unit, combining the adhesive barrier and pouch.
- Two-piece pouches have a separate adhesive barrier and pouch that can be attached or detached from each other.

Colostomy pouches are available in different sizes, shapes, and materials, including disposable and reusable options. The



Fig.4.7: COLOSTOMY POUCH

healthcare provider will recommend the most suitable pouch based on the stoma's location and the individual's needs.

It is important to empty the pouch regularly and replace it when necessary. Proper care of the colostomy pouch can help prevent leaks, skin irritation, and infection.

Another classification of colostomy pouch is: closed and drainable.

- Closed colostomy pouches are designed to be used once and then disposed of. These pouches are typically used for people who have a predictable bowel routine, and the stoma output can be easily managed.
- Drainable colostomy pouches are designed to be emptied and reused. These pouches typically have an opening at the bottom that can be emptied into a toilet or a container. They can be emptied multiple times throughout the day, as needed. Drainable pouches are useful for people who have irregular bowel movements or a higher output from the stoma.

# **Closed Ostomy Pouch**



Fig.4.8: OPEN OSTOMY POUCH

# **Drainable Ostomy Pouch**



Fig.4.9: DRAINABLE OSTOMY POUCH

# **Colostomy irrigation**

Colostomy irrigation involves instilling a large volume of water into the stoma and colon, stimulating the bowel to empty its contents. This is done using an irrigation set consisting of a bag or container to hold the water, a tubing system, and a cone-shaped irrigation tip inserted into the stoma. Colostomy irrigation can benefit some people with a colostomy, as it can help them achieve a more predictable and controllable bowel movement pattern. It may also reduce the need for a collection bag and can help with skin irritation around the stoma. Patients with a stoma can be referred to a stoma nurse or a palliative care nurse to train themselves in stoma irrigation.

## Specific teaching points to the patients.

## Diet

A person with a stoma does not require a special diet. Like any other individual, they require a healthy and balanced diet. Some dietary products can be odour-producing and gas-forming which the patient may have difficulty in managing. The patients learn themselves over time to adapt to different dietary foods. It is important to avoid time release and enteric-coated tablets as they are not absorbed completely.

The following are some food items and their effect on patients with ostomies.

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

## Travel, work, dressing, and sports:

Patients with a colostomy can travel like any other person. They may need to carry extra bags if they need immediate change. Patients can engage in routine work that do not involve heavy lifting and strenuous exercise as an increase in intra-abdominal pressure can cause the stoma to prolapse or hernia. The pouch can be comfortably worn underneath the clothes and is easily concealed. It is safe to avoid contact sports that can cause injury to the stoma like kabaddi, football etc.

## Problems faced by patients with colostomy

## **Dehydration:**

- Except in sigmoid colostomy and descending colon colostomy, there is water loss through other stomas. These patients are at risk of dehydration if they do not consume adequate water. On average, colostomy patients must drink 1.5 to 2L fluid per day.
- It is recommended that they always carry water with them and 'drink little and drink often'.

## **Constipation and Diarrhoea:**

- Constipation in patients with an ostomy is usually due to inadequate water intake. Usually, constipation can be managed by increasing fluid intake and soluble dietary fibre. Insoluble dietary fibres can cause temporary obstruction and cramps. Some patients may require laxatives to manage constipation.
- Diarrhoea could be due to various causes, including diet, stress, and medications. Sometimes raw fruits, vegetables, fruit juices, and milk can temporarily produce loose stools. It is important to differentiate diarrhoea from loose stools normally seen in more proximal stomas
- Diarrhoea that is of infective origin will require medical management. Since patients with a stoma tend to lose more electrolytes, hydration and replenishing electrolytes are crucial when the patient has diarrhoea.

## Peristomal skin problems:

• If **skin erosion** is present, apply karaya powder mixed with egg white for 2 to 3 days.Zinc oxide paste can be used instead of karaya powder.

- The right size of skin barrier around the stoma and application of barrier cream to protect and prevent skin irritation.
- Some patients can be allergic to pouching products: Choosing the right pouching system is crucial in such cases.
- Advise daily cleaning with soap and water and drying with soft towel (mopping).

## Caring for the psychological needs of the patient

- Though an ostomy can be lifesaving surgery, these patients will require education, constant motivation, supportive counselling, and care to cope with this major lifestyle modification.
- Concerns such as fear of leakage, physical problems, body image change, embarrassment due to odour, noisy flatulence, and privacy need to be individually addressed in all patients to improve their quality of life.
- Having a colostomy should not interfere with sexual activity.
- Counselling the patient and the spouse and exploring questions they might have, fears, and hopes is very important in improving the patient's and family's quality of life.
- Physical problems such as skin irritation and excoriation affect patients' quality of life, increasing their distress. Hence, impeccable assessment and prompt management of physical problems will lead to a better quality of life and improved psychological well-being.

## SUBCUTANEOUS INJECTION

**Subcutaneous injection** is a method of administering medication into the layer of tissue directly beneath the skin. This route of administration is commonly used for medications that are absorbed slowly and steadily into the bloodstream. It is a convenient alternative route of the parenteral route of drug administration. Family members can also learn to give necessary injections at home using this route.

# Subcutaneous infusions or hypodermoclysis

It is the 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 subcutaneous route is on par with intravenous (IV) administration.

#### **Subcutaneous catheters**

Subcutaneous catheters are devices that are secured at the insertion site to facilitate intermittent subcutaneous injections or infusions. A 26G IV cannula/24-26 G Scalp vein needle can be used for subcutaneous infusions

# How to select an appropriate site for subcutaneous infusion:

- The site should have a 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.



### Fig.4.10: COMMON SITES FOR SC INJECTIONS

- Alternate the sites on a regular basis.
- A subcutaneous needle can be in place for a maximum period of 5-7 days

## **Indications for using SC route**

- Persistent, Nausea and Vomiting
- Dysphagia.
- Intestinal obstruction.
- Coma.
- Poor absorption of oral drugs.
- Terminal care.

## Contraindicated sites for subcutaneous infusion

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

## Drugs commonly given through in subcutaneous Route

- Inj .Midazolam
- Inj. Hyosine butylbromide
- Inj Dexamethasone
- Inj. Morphine
- Inj Oxycodone
- Inj. Levomepromazine
- Inj. Haloperidol
- Inj. Cyclizine
- Inj. Metoclopramide

### Drugs to be avoided in subcutaneous injections

- Promethazine
- Chlorpromazine
- Potassium chloride
- Calcium gluconate
- Phenytoin
- Paracetamol

## Complications

- Redness
- Swelling
- Tenderness
- Pain
- Warmth

## Instructions for family caregivers following subcutaneous needle placement

- 1. Carers may be instructed on necessary hygiene measures for handling the materials for administering medicines
- 2. Lumping under the skin is normal after the administration of subcutaneous injections. These lumps will disappear within minutes to hours.

- 3. Swelling after the subcutaneous infusion is normal. This swelling will resolve on its own within a few hours.
- 4. Drugs that are refrigerated should be warmed to room temperature before administration.
- 5. 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.

Subcutaneous infusion is a valuable tool in palliative care to manage symptoms and improve the patient's quality of life. The nurse's role in administering subcutaneous infusions is critical to ensure safe, effective medication administration and provide compassionate care to patients and their families.

# **ORAL HYGIENE**

## Introduction

Mouth care/ Oral Hygiene is an important aspect of overall health, particularly in palliative care where patients may experience discomfort or pain related to oral health problems. Oral issues are common in patients receiving palliative care and can significantly impact their quality of life. These issues can include dry mouth, oral infections, oral mucositis, difficulty swallowing, and pain. Good mouth care practices can help prevent infections, reduce pain, and promote patient comfort.

Perhaps most importantly, these complications impair oral health with various consequences, including malnutrition, anorexia, and cachexia. In addition, psychological disturbances related to the oral cavity's role in communication, social life, and pleasures associated with eating.

## **Risk factors**

- Debility
- Dry mouth
- Chemotherapy
- Poor oral intake
- Local irradiation
- Dehydration

## **Purpose of Oral Hygiene**

- To promote hygiene
- To remove debris
- To provide refreshment
- To prevent and infection
- To prevent and treat dryness and halitosis
- To promote a sense of well being

### **Frequency of oral care**

The frequency of oral care depends upon the condition of the patients.

- Healthy individuals require only twice-daily brushing.
- 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.

### Oral hygiene

Oral hygiene is an important aspect of palliative care as it helps to maintain a patient's overall comfort and well-being. Nurses should monitor patients for signs of oral health problems, such as cavities, gum disease, and mouth sores. If these issues arise, appropriate treatments should be provided to help alleviate discomfort and prevent complications.

## **Common Oral Problems**

- Aphthous ulcers, also known as canker sores, are small, painful, shallow ulcers that can develop on the soft tissues inside your mouth, including your lips, cheeks, gums, and tongue. They are not contagious and usually go away on their own within one to two weeks.
- **Stomatitis** is a general term for inflammation of the mouth and lips. Symptoms can include redness, swelling, and sores in the mouth, as well as pain and difficulty eating and drinking. A variety of factors, including viral, bacterial, or fungal infections, allergies, and irritants such as tobacco or certain foods can cause it.
- **Gingivitis** is a type of gum disease that occurs when the gums become inflamed and swollen due to a buildup of plaque on the teeth. Symptoms can include bleeding gums, bad breath, and gum sensitivity. If left untreated, gingivitis can lead to more serious forms of gum disease and tooth loss. Practicing good oral hygiene, including regular brushing and flossing, is important to prevent and treat gingivitis.
- **Dry mouth**, also known as xerostomia, is a common oral issue in palliative care patients. Various factors, including medications, radiation therapy, and dehydration can cause it. A dry mouth can lead to difficulty speaking, swallowing, and tasting and increased risk of oral infections. Palliative care teams may manage dry mouth with frequent sips of water or ice chips, saliva substitutes, and avoiding caffeine and alcohol.
- **Oral infections,** such as candidiasis and herpes simplex virus, can cause pain and discomfort in palliative care patients. These infections may be treated with antifungal, antiviral, or antibiotic medications.
- **Oral mucositis,** inflammation and ulceration of the oral mucosa, can be a side effect of chemotherapy or radiation therapy. It can cause pain, difficulty swallowing, and increased risk of infection. Palliative care teams may manage oral mucositis with topical analgesics, such as lidocaine, and mouthwashes containing saline or sodium bicarbonate.
- **Difficulty swallowing,** also known as dysphagia, can be caused by various factors, including neurological disorders, cancer, and radiation therapy. In severe cases, patients with dysphagia may require a modified diet, such as pureed or soft foods, or even tube feeding. Speech-language pathologists can provide assistance with swallowing exercises to help improve swallowing function.
- **Pain** is a common oral issue in palliative care patients and can be caused by various factors, including oral infections, mucositis, and cancer. Non-opioid analgesics, such as acetaminophen or nonsteroidal anti-inflammatory drugs (NSAIDs), may be used for mild pain, while opioids, such as Morphine or fentanyl, may be necessary for severe pain
- Halitosis, also known as bad breath, is a condition that causes unpleasant odors in the mouth. A variety of factors, such as poor oral hygiene, food debris, dry mouth, gum disease, and infections, can cause it. Treatment may involve improving oral hygiene habits, using mouthwash, and addressing any underlying health conditions.
- **Candidiasis**, also called oral thrush, is a fungal infection that can occur in the mouth. It is caused by Candida yeast and may appear as white patches on the tongue, inside the cheeks, or on the roof of the mouth. It can be common in individuals with weakened immune systems, such as those undergoing chemotherapy or who have HIV/AIDS. Treatment may involve antifungal medication or improving oral hygiene.

## Management of Oral Issues in Palliative Care

In palliative care, patients may have difficulty performing regular oral hygiene practices due to weakness, fatigue, or other physical limitations. Therefore, it is important for healthcare providers to assist with oral care as needed.

Some important oral hygiene practices for patients in palliative care include:

- 1. **Brushing teeth and tongue:** Patients should brush their teeth at least twice a day using a softbristled brush and fluoride toothpaste. They should also gently brush their tongue to remove bacteria and prevent bad breath.
- 2. **Flossing:** Patients should floss at least once a day to remove plaque and food particles from between their teeth.
- 3. **Mouthwashes or rinses**: Patients may benefit from using mouthwashes or rinses to help kill bacteria and freshen breath. Mouth rinses can be an important part of oral care for patients in palliative care, as they can help to reduce inflammation, kill bacteria, and promote overall oral health. Healthcare providers should recommend products that are safe for patients with sensitive or dry mouths. Here are some common mouth rinses that may be recommended for patients in palliative care:
  - Salt water rinse: A simple and effective rinse can be made by mixing a teaspoon of salt in a cup of warm water. This can help to reduce inflammation and kill bacteria in the mouth.
  - **Baking soda rinse:** Mixing a teaspoon of baking soda with a cup of warm water can help to neutralise acids in the mouth and promote a healthy pH balance. This can be particularly helpful for patients with dry mouth or who are at risk of developing cavities.
  - **Chlorhexidine rinse:** This prescription-strength mouth rinse can help to kill bacteria and prevent infections in the mouth. It may be recommended for patients at high risk of developing oral health problems, such as those who are bedridden or have weakened immune systems.
  - Saline rinse: Saline rinse is a gentle and soothing rinse that can help to moisturise the mouth and reduce dryness. It is particularly helpful for patients experiencing side effects from medications that cause dry mouth.
  - Lidocaine rinse: This prescription-strength mouth rinse contains a local anaesthetic that can help to numb the mouth and reduce pain. It may be recommended for patients experiencing oral pain or discomfort due to conditions such as mucositis or oral thrush.
- 4. In addition to mouth rinses, several other mouth care agents may be used in palliative care to promote oral health and alleviate discomfort. Here are some common mouth care agents:
  - **Moisturisers:** Moisturisers can help reduce mouth dryness and prevent discomfort. Products such as saliva substitutes or oral lubricants may be recommended for patients with dry mouth.
  - **Topical anaesthetics:** Topical anaesthetics can help to numb the mouth and reduce pain, particularly for patients with mucositis or other painful oral conditions. These may include gels or sprays containing lidocaine or benzocaine.
  - Antifungal agents: Patients who develop oral thrush or other fungal infections in the mouth may benefit from antifungal agents, such as Nystatin or Fluconazole.
  - Antiseptics: Antiseptics can help to kill bacteria and prevent infections in the mouth..
- **Corticosteroids:** Patients with severe inflammation or pain in the mouth may benefit from corticosteroids, which can help to reduce inflammation and pain. These may be prescribed as a mouthwash, spray, or tablet.
- 5. **Denture care:** Patients who wear dentures should be instructed to remove and clean them daily to prevent infections and irritation.

**Hydration:** Adequate hydration is important for oral health as it helps to prevent dry mouth, which can increase the risk of cavities and gum disease

# NASO-GASTRIC TUBE MANAGEMENT

Nasogastric (NG) feeding is a method of delivering nutrition and fluids to patients who are unable to take food orally. It involves passing a thin, flexible tube through the nose, throat, and stomach to deliver nutrients and medications directly to the patient's digestive system. In palliative care, NG feeding may be used in patients who have lost their ability to eat or drink. However, the decision to use NG feeding should be carefully considered in the context of the patient's goals of care, quality of life, and symptom management.

When using NG feeding in palliative care, it is important to:

- Ensure that the patient or their caregiver understands the benefits and potential risks of NG feeding.
- Monitor the patient closely for any signs of discomfort, aspiration, or other complications.
- Provide adequate pain and symptom management to minimise discomfort and improve quality of life.
- Use NG feeding as part of a comprehensive palliative care plan that includes symptom management, emotional and spiritual support, and family involvement.
- Reassess the need for NG feeding regularly and adjust the treatment plan based on the patient's evolving condition and goals of care.

## Nasogastric tube feeding

Articles needed: Dry towel, 20ml syringe, a glass of water, a glass of liquid food.

## **Preparation of liquid food**

Simple home foods can be used depending on the patient's choice and what is available. This can include foods such as porridge, rice gruel, soup, juice, milk or curd. More solid foods such as idly, fish, vegetables, dals or meat can be used if cooked well and ground finely. The usual food cooked for the family can also be used. Any food to be given should be ground finely with a mixer or mashed with a large spoon. The liquid is added to make a thin consistency and then filtered through a strainer such as that used for tea. Patients who cannot swallow can still taste a tiny amount which can give pleasure.

## **Procedure of feeding**

- Place the patient in a sitting position. If unable to sit, place 2-3 pillows under the head and shoulders
- Wash hands well with soap and water.
- Place a dry towel around the neck to catch any spills.
- Fix the syringe to the end of the nasogastric tube.
- Gently pull back and make sure it fills with stomach contents. This checks the tube is still in the correct place in the stomach.
- Take off the syringe and remove the central piston or inner tube from the syringe.
- Re-fix this outer part of the syringe to the end of the tube.

- Pinch the tube to prevent air from going down the tube.
- Hold the end of the tube about 12 inches above the patient's head.
- Slowly pour the prepared liquid food, fluid or drugs into the outer syringe. It should flow slowly and steadily. Do not force fluids to go through.
- Take care not to let air enter, as this will cause wind and discomfort for the patient.
- Flush the tube at the end of the feed by pouring enough drinking water to clear the tube. Around half a small cup (50ml)
- Give small amounts of feed regularly. Usually, a small cup or 150 ml is enough.
- Remember to add salt to the feeds. Most patients require around two teaspoons of salt per day.
- Once every 3-4 days, repeat this procedure using only warm saline solution to clean thoroughly and prevent coating of the tube, which may lead to blocking.
- Occasionally change the sticking plaster that keeps the tube attached to the nose. This is not needed every time.

## Troubleshooting

- If the fluid is not flowing well, then first check it is still in place by looking for stomach contents when you pull back on the syringe. You may also notice that the tube has slipped out and appears much longer.
- If the tube is in the correct place, it may be becoming blocked so increase the number of times you flush and clean it with warm saline. Using soda bicarb solution to flush may be more effective.
- If the tube has come out of the stomach or is completely blocked, you will need to seek advice from your doctor or nurse.

# **TRACHEOSTOMY CARE**

A tracheostomy is an artificial opening made into the trachea into which a tube is inserted to establish and maintain a patent airway. Tracheostomy care refers to maintaining and cleaning the tracheostomy site and the tube inserted into the trachea to facilitate breathing.

## **Tracheostomy Tube**

A tracheostomy tube is a medical device that is inserted into the trachea (windpipe) through a surgical opening in the neck called a tracheostomy. The tube provides an alternate airway for breathing and can be used to manage respiratory conditions such as upper airway obstruction or respiratory failure.

Here are some key features of a tracheostomy tube:

1. **Types:** There are different types of tracheostomy tubes available, including cuffed and uncuffed tubes, fenestrated tubes, and speaking valves. The choice of tube depends on the patient's condition and needs.



Fig. 4.11: TRACHEOSTOMY TUBE

 Size: Tracheostomy tubes come in different sizes, and the appropriate size is determined based on the patient's age, gender, and neck size. Using the correct size tube is important to prevent complications such as airway obstruction or tracheal injury.

## **Components of a tracheostomy tube**

- A tracheostomy tube is a medical device that is inserted into the trachea (windpipe) through a surgical opening in the neck called a tracheostomy. Here are the parts of a tracheostomy tube:
- 1. Outer cannula: This is the main part of the tracheostomy tube that sits in the trachea. It is a curved tube with a flange at the base to secure it.
- 2. Inner cannula: This is a removable tube that sits inside the outer cannula. It can be removed for cleaning or replaced if it becomes clogged.
- 3. Cuff: Some tracheostomy tubes have an inflatable cuff that sits around the outer cannula. When inflated, the cuff creates a seal between the tracheostomy tube and the tracheal wall to prevent air leaks or aspiration of secretions.
- 4. Pilot balloon: This small balloon is attached to the cuff and allows healthcare providers to monitor the pressure inside the cuff.

A metal tracheostomy is a more commonly used tube with an outer and inner cannula in palliative care. The metal tracheostomy tube is made of a biocompatible metal, such as stainless steel or titanium, and is designed to be left in place for an extended period.

Compared to plastic tracheostomy tubes, metal tracheostomy tubes are more durable and resistant to damage, which can be especially important for patients who require long-term breathing support.



• Outer cannula: Outer cannula is held in place by Fig. 4.12: METAL TRACHEOSTOMY a ribbon or tie, which is passed through the loops on either side of the opening of the tube.

• Inner cannula: Fits inside the outer cannula. The inner tube is held in place by a small flip lock located on the top of the outer tube.

# **Tracheostomy Care**

Tracheostomy care involves maintaining the cleanliness and patency of the tracheostomy tube and surrounding area to prevent infection and ensure proper breathing.

## 1. Routine care

- Always wash hands thoroughly with soap and water or use hand sanitiser before performing tracheostomy care.
- · Check the tracheostomy tube for proper placement, patency, and any signs of dislodgement or obstruction. Notify the healthcare provider immediately if there are any concerns.
- Clean the skin around the tracheostomy tube with a clean, damp cloth or sterile saline solution. Protect the skin with a gauze pad, cut in the middle to be placed between the outer tube and the skin. Gently remove any crusts or debris around the stoma.

Cleaning inner tube - thorough cleaning of the inner tube should be done regularly.

Portex tube: Remove the inner tube, clean it under running water, rinse it with normal saline, and replace it. If secretions are present, soak the inner tube in the normal saline to soften the secretions and clean under running water using a cut piece of the suction catheter or brush. Then clean the tube with normal saline or soap and wa, gently tap the tube, ensure that the lumen is clean and no water is left inside the tube, and replace it.

- Metal tube: Remove the inner tube, clean it under running water, soak it in a solution of normal saline and replace it. If secretions are present, soak the inner tube in the normal saline to soften the secretions and clean under running water using a cut piece of the suction catheter or brush. Then sterilise by putting it in boiling water for 5 minutes and ensure that the lumen is clean and no water is left inside the tube, before replacing it.
- The inner tube must be removed and washed under cold running water. Soak it in a solution of normal saline to soften the secretions. Then clean it with soap and water and sterilise it by putting it in boiling water for 5 minutes. Then re-insert it and lock it.
- The outer tube should not be removed. Clean the tube plates thoroughly with gauze soaked in saline.
- Care should be taken not to allow the cleaning solution to enter the stoma while cleaning. It may be aspirated into the lungs.
- Train the patient to clean the tube by themself using a mirror.
- Oral hygiene to be maintained
- Prevent entry of insects into tracheostomy tube.
- Prevent the entry of water directly in to the stoma while bathing, swimming, and shaving

## 2. Suction

As far as possible help the patient to cough out the secretions, postural drainage is helpful to bring out the secretions. Steam inhalation will help to loosen the secretions. Suction the tracheostomy tube as needed to remove secretions and maintain airway patency.

## 3. Humidification of air

Place wet sterile gauze (soaked in tap water) on the tracheostomy tube. This helps humidify the inhaled air and filters the dust. Use a humidifier or nebuliser to moisten the air and prevent dryness in the tracheostomy tube and airway.

## 4. Skincare

Clean the skin around the tracheostomy site with gauze soaked in saline. Protect the skin with a gauze pad, cut in the middle to be placed between the outer tube and the skin.

## 5. Changing the tie

Tie is used to fix the tube in position. Use sterile gauze o and secure it with a sterile tie or tape. Change the tracheostomy dressing once in three days or whenever soiled.

## 6. Speech therapy and communication

The Patient is advised to take a deep breath, close the stoma with a finger, and speak. They may be provided with a calling bell or paper and pen for communication. Inform the patient to report any discomfort or changes in breathing. Ensure the patient or caregiver is informed and educated on tracheostomy care and potential complications.

## **Common problems in tracheostomy patients**

Here are some common problems associated with tracheostomy:

- **Infection:** Tracheostomy can increase the risk of infection, particularly if the site is not properly cared for or if the patient has a weakened immune system.
- **Blockage:** The tracheostomy tube can become blocked with mucus, secretions, or other debris, which can cause breathing difficulties.

- **Dislodgment:** The tracheostomy tube can become dislodged or accidentally removed, which can lead to airway obstruction and difficulty breathing.
- **Bleeding:** Bleeding can occur during or after the tracheostomy procedure, which can be life-threatening if not promptly treated.
- Air leak: An air leak can occur around the tracheostomy tube, which can cause difficulty breathing and increase the risk of infection.
- **Granulation tissue:** Granulation tissue can form around the tracheostomy site, which can cause irritation, bleeding, and difficulty breathing.
- Vocal cord paralysis: Vocal cord paralysis can occur if the nerves that control the vocal cords are damaged during the tracheostomy procedure, which can cause hoarseness and difficulty speaking.
- Choking of the Patient due to dropping of food or water into the tracheostomy opening

It's important to monitor patients with tracheostomy regularly for signs of these and other potential problems and to promptly report any concerns to a healthcare provider. Regular tracheostomy care can also help prevent or manage these complications.

# ASSISTING IN THORACOCENTESIS

Thoracentesis is a medical procedure used to remove excess fluid from the pleural cavity, which is the space between the lungs and the chest wall. This procedure can be used in palliative care to relieve symptoms caused by pleural effusions, such as difficulty breathing and chest pain. However, the decision to perform thoracentesis in palliative care should be made on a case-by-case basis, considering the patient's overall condition and goals of care. In some cases, the risks and discomfort associated with the procedure may outweigh the potential benefits, especially if the patient has a limited life expectancy or if the fluid buildup is not causing significant symptoms.

If thoracentesis is deemed appropriate for a palliative care patient, it is important to ensure that the procedure is performed with sensitivity to the patient's comfort and emotional needs. This may include providing pain management, using a calming environment, and offering emotional support and reassurance throughout the procedure.

Nurses play an important role in thoracentesis procedures before, during, and after the procedure. Here are some of the key responsibilities of a nurse in the context of thoracentesis:

- 1. **Pre-procedure preparation:** The nurse may be responsible for preparing the patient for the procedure by explaining what to expect, providing reassurance and support, and ensuring that the patient is comfortable and well-informed. The nurse may also help to obtain consent for the procedure and ensure that the patient has fasted appropriately if necessary.
- 2. Assisting during the procedure: During the thoracentesis procedure, the nurse may assist the physician or other healthcare provider by helping to position the patient correctly, monitoring vital signs, providing emotional support and distraction, and handing over any necessary equipment or supplies.
- 3. **Patient monitoring:** After the procedure is complete, the nurse may be responsible for monitoring the patient for any adverse effects, such as bleeding, pain, or difficulty breathing. The nurse may also be responsible for documenting the procedure and any relevant information about the patient's condition. After the procedure, the patient will be monitored for any signs of complications, such as bleeding, infection, or pneumothorax. The patient may also be advised to avoid strenuous activity and rest for a period.

- 4. **Patient education:** The nurse may also play a crucial role in educating the patient and their family about the procedure, the expected outcomes, and potential risks or complications. This can help to ensure that the patient is well-informed and can make informed decisions about their care.
- 5. **Providing emotional support**: Thoracentesis can be a stressful and anxiety-provoking experience for patients, so nurses may also provide emotional support and reassurance throughout the procedure. This may include offering relaxation techniques, providing a calming presence, and encouraging the patient to express their feelings and concerns.

The nurse's role in thoracentesis is to support the patient and ensure their comfort and safety throughout the procedure while providing education and emotional support to the patient and their family.

# ASSISTING IN INDWELLING ASCITIC CATHETER PLACEMENT

Ascites is a medical condition characterized by the accumulation of excess fluid in the abdominal cavity. Various underlying medical conditions, including liver disease, heart failure, kidney disease, and cancer, can cause it. Ascites is a common symptom in patients receiving palliative care. When ascites is present, the abdomen may appear swollen or distended, and the patient may experience discomfort or pain. In addition to the physical symptoms, ascites can also lead to complications such as infection, hernias, and difficulty breathing. In patients with advanced cancer or other life-limiting illnesses, ascites can be a significant source of discomfort and distress.

Treatment for ascites depends on the underlying cause and may include medications, lifestyle changes, and procedures such as **paracentesis** (removal of excess fluid through a needle), **placement of an indwelling ascitic catheter** (a medical device used to drain excess fluid from the abdomen), or surgery. In palliative care, ascites management focuses on relieving symptoms and improving the patient's comfort. This may involve the use of medications to reduce fluid retention, such as diuretics. In some cases, paracentesis (removal of excess fluid through a needle) may be necessary to provide immediate relief of symptoms.

If paracentesis is required frequently or for an extended period, an indwelling ascitic catheter may be inserted to provide ongoing drainage of fluid. The indwelling catheter allows for regular drainage of the fluid and can be managed at home by the patient or a caregiver. This can help to improve the patient's comfort and reduce the need for frequent hospital visits.

Palliative care teams also focus on providing emotional and spiritual support to patients and their families. This may include counselling, social support, and other resources to help patients cope with advanced illness's physical and emotional challenges.

## **Indwelling Ascitic Catheter**

An indwelling ascitic catheter is a medical device used to drain excess fluid from the abdominal cavity in patients with ascites. The indwelling ascitic catheter is inserted through a small incision in the abdominal wall and into the peritoneal cavity. The catheter is typically made of silicone or polyurethane and is designed to remain in place for an extended period, allowing for fluid drainage. The catheter is attached to a drainage bag or bottle, which collects the fluid. The drainage bag or bottle can be emptied and replaced as needed, either by the patient or a caregiver, or during regular medical visits.

## Role of nurse in assisting in indwelling ascitic catheter placement

A nurse's role in placing an indwelling ascitic catheter is critical in ensuring the procedure is performed safely and that the patient receives appropriate care and support. Some specific roles and responsibilities of nurses during indwelling ascitic catheter placement may include:

- Assessment: The nurse assesses the patient's medical history, current condition, and suitability for an indwelling ascitic catheter. This includes assessing for any contraindications to catheter placement and ensuring that the patient is informed about the procedure.
- **Pre-procedure care:** Nurses can help prepare the patient for the procedure by explaining the procedure, obtaining informed consent, and ensuring that the patient is in a comfortable position. They can also help the healthcare provider prepare the equipment and sterile supplies needed for the procedure.
- **Intra-procedure care:** Nurses can assist the healthcare provider during the procedure by helping to position the patient, providing emotional support to the patient, and monitoring the patient's vital signs. They can also help to maintain the sterile field and assist with the insertion of the catheter.
- **Post-procedure care:** Nurses can monitor the patient after the procedure for any complications, such as bleeding or infection. They can also educate the patient on how to care for the catheter site, including how to perform regular dressing changes and signs and symptoms to watch for that may indicate an infection or other complications.
- **Ongoing care:** Nurses can provide ongoing care to patients with indwelling ascitic catheters by monitoring the catheter site for any signs of infection or complications and performing regular dressing changes.
- Education: Nurses can provide education to patients and their families on how to care for the indwelling ascitic catheter, including proper hygiene, dressing changes, how to properly dispose of drainage bags, and how to contact their healthcare provider in case of any concerns or issues. The nurse may also provide information about how to recognise signs of infection or other complications.
- **Documentation** in ascitic tapping includes the following:
  - **Patient information:** This includes the patient's name, age, medical history, and any relevant allergies or medications.
  - **Procedure details:** This includes the date and time of the procedure, the site of the paracentesis, the size and type of needle used, the amount of fluid removed, and the presence of any complications or adverse events during the procedure.
  - Vital signs: This includes the patient's pre-procedure vital signs, such as blood pressure, heart rate, respiratory rate, and oxygen saturation.
  - **Fluid analysis:** This includes the results of any laboratory tests performed on the fluid obtained during the paracentesis, such as cell count, protein and albumin levels, and culture and sensitivity results.
  - **Patient response:** This includes the patient's response to the procedure, including any changes in vital signs or symptoms and any adverse events or complications that may have occurred.
  - **Plan of care:** This includes the plan for ongoing management of the patient's ascites, such as medication management or the need for further paracentesis or other procedures.

## Conclusion

Nurses play a crucial role in providing palliative care to patients. Some of the specific tasks that nurses may perform include:

- 1. Assessing and managing symptoms: Nurses are responsible for assessing the patient's symptoms, including pain, signs of infection, nausea, and anxiety, and providing appropriate interventions to manage these symptoms.
- 2. Providing emotional support: Nurses play a vital role in providing emotional support to patients and their families. This may involve listening to concerns, providing reassurance, and offering counseling services.

- 3. Coordinating care: Nurses are responsible for coordinating the patient's care, including communicating with other healthcare professionals, arranging for home care services, and making referrals to other specialists as needed.
- 4. Educating patients and families: Nurses may educate patients and their families about the disease process, treatment options etc

# LYMPHOEDEMA MANAGEMENT

### Introduction

Lymphoedema is an accumulation of lymph in the interstitial space of subcutaneous tissue or is an excessive and persistent accumulation of extravascular and extracellular fluid and proteins in tissue spaces. It occurs when lymph volume exceeds the capacity of the lymph transport system and is associated with the disturbance of the water and protein balance across the capillary membrane.

### **Pathophysiology**

Obstruction or damage blocks the lymphatic system with gradual dilatation of the lymph vessels leading to incompetent valves and increasing pressure inside the vessels. The fluid tends to drain into the interstitial space by diffusion, resulting in lymph stasis.

## **Classification of Lymphedema**

- **1. Primary lymphedema:** This type of lymphedema is caused by a congenital defect in the lymphatic system, leading to abnormal lymphatic drainage and fluid buildup.
  - **Congenital lymphedema:** This type of primary lymphedema is present at birth or develops within the first two years of life.
- 2. Secondary Lymphedema: This type of lymphedema occurs as a result of damage to the lymphatic system, usually as a result of cancer treatment (such as surgery, radiation, or chemotherapy) or infection.
  - **Cancer-related lymphedema:** This is caused by cancer treatments that damage the lymphatic system, such as surgery or radiation therapy.
  - Non-cancer-related lymphedema: This is caused by infections (such as filariasis) or other conditions that damage the lymphatic system, such as trauma or surgery.



Fig.4.13: LYMPHEDEMA

# Signs and Symptoms of Lymphedema

- Slow onset Swelling: Slow onset swelling is a common symptom in lymphedema, which refers to the gradual development of swelling over time. Usually unilateral unless the disease/extensive trauma is present.
- Non-pitting oedema: Non-pitting edema is a type of swelling that occurs when pressure is applied to the affected area and does not leave an indentation, as opposed to pitting edema, which leaves an indentation when pressure is applied. In people with lymphedema, non-pitting edema is a common symptom that occurs due to the accumulation of lymphatic fluid in the affected limb or area.
- Skin changes: dry, thickened skin, deep creases. Peaud's orange appearance,
- Stemmer's sign: inability to pinch a fold of skin at the base of the second digit.
- **Hyperkeratosis:** thickening of the outer layer of the skin, known as the epidermis. In people with lymphedema, hyperkeratosis can occur as a result of chronic swelling, which can cause skin changes and thickening over time.
- **Papillomatous lesion:** abnormal growths or warts that can occur on the skin's surface in people with lymphedema. These growths can develop in areas of the skin that are affected by lymphedema due to chronic inflammation, poor lymphatic flow, and impaired immune function.
- **Lymphorrhoea:** lymphatic fluid leaks from the skin's surface due to damage or obstruction of the lymphatic vessels. The lymphatic fluid is a clear fluid that circulates throughout the lymphatic system and plays a crucial role in immune system function.
- Joint stiffness and muscle strain
- Discomfort, heaviness, and pain

## Some of the problems that people with lymphedema may face include:

- **Swelling:** The most common symptom of lymphedema is swelling in the affected limb or area, which can cause discomfort, heaviness, and limited mobility.
- **Infection:** The accumulation of lymphatic fluid in the affected area can create a breeding ground for bacteria, leading to infections such as cellulitis or lymphangitis.
- Skin changes: Lymphedema can cause changes to the skin in the affected area, such as thickening, hardening, or discolouration, which can make it more susceptible to infections, ulcers, or wounds.
- **Reduced flexibility:** Swelling and stiffness in the affected limb or area can reduce flexibility and range of motion, making it difficult to perform daily activities or exercise.
- **Pain:** Lymphedema can cause pain and discomfort in the affected limb or area, affecting the quality of life and leading to depression or anxiety.
- Emotional impact: Living with lymphedema can be challenging, and it can affect a person's emotional well-being, self-esteem, and body image.
- **Financial burden:** Lymphedema treatment, such as compression garments, bandaging, or manual lymphatic drainage, can be expensive and may not be covered by insurance, which can create a financial burden for people with lymphedema.

## **Psychological issues**

- Altered body image
- Anxiety and depression
- Reduced adjustment to illness
- Difficulty in wearing clothes
- Reduced working capacity
- Reduced social contact

• In cancer, fear of recurrence

# Aim of lymphoedema care

- To maintain a healthy tissue condition
- To reduce the risk of infection, Daily care
- Meticulous hygiene
- Inspection of the limb and adjacent trunk
- Moistening of limb and adjacent trunk

# Four cornerstones of management

- 1. Skincare
- 2. Compression (bandage/hosiery)
- 3. Massage
- 4. Exercises
- 1. **Skincare:** Proper skin care is essential in managing lymphedema. People with lymphedema are at higher risk of skin infections, so keeping the skin clean and moisturised can prevent bacterial infections and reduce the risk of skin breakdown.

# Health Teaching for Skin Care

- Wash the affected arm with water.
- Keep the skin clean and moist.
- Do not use too much soap, which will dry the skin. Use only mild soap.
- Give special attention to creases between digits and joints.
- Avoid perfumes.
- Pat dry with a soft, clean towel.
- Do not rub the affected limb.
- Apply coconut oil from the distal to the proximal end of the limb.
- Use loose clothing.
- Avoid
- Injections in the swollen arm, including blood sampling
- $\circ$  Blood pressure measurement on the swollen arm.
- Vene punctures
- Jewellery on the affected limb
- Injury to the limb
- Lifting heavy weight
- Mosquito bites
- Take care when cutting toe nails or fingernails using a nail cutter.
- Treat cuts, scratches insect bites promptly by cleaning well and applying antiseptic cream or solution.
- Seek medical aid if the skin becomes red and inflamed.
- Protect from direct heat/sunlight.
- If lymphorrhoea or any injury, clean with saline and apply a sterile dressing.
- If cellulitis do not start lymphedema care, treat cellulitis.
- 2. **Compression**. Compression therapy involves applying pressure to the affected area to reduce swelling and improve lymphatic flow. This can be achieved through various techniques, such as wearing compression garments, bandaging, or pneumatic compression devices. Compression therapy helps to maintain the reduced size of the limb after it has been reduced by manual lymph drainage.

- Compression can be given with proper bandaging and unique hosiery.
- Before applying compression, measurements of both limbs should be recorded and repeated every six months.

## **Benefits of Compression**

- Improved lymph drainage.
- Improve movement and function of the limb.
- Improve distorted limb shape.
- Improve thickened fibrotic skin.

Bandaging: Bandaging in lymphedema involves wrapping the affected limb or area with specialised

bandages designed to provide compression. The bandages are applied in a specific sequence, starting at the base of the limb and working upward, to encourage lymphatic fluid to flow towards the trunk. The bandages are designed to provide more compression at the base of the limb and gradually decrease in compression as they move upward.

The duration and frequency of bandaging will depend on the severity of the lymphedema and the individual's specific needs. In general, bandages may be worn for several days or weeks at a time and should be changed and re-applied by a trained healthcare professional. Bandaging also helps limit fluid accumulation in the subcutaneous tissue and provides the muscles with a firm outer casting by stimulating lymph flow.



Fig.4.14. LYMPHEDEMA BANDAGING

# **Principles of bandaging**

- Apply graduated pressure.
- Reshape limb in a cylindrical manner with cotton and gamgee pad and crepe bandage.
- Apply for 24 hrs (most preferred)
- Low resting pressure increases during exercises.

### Procedure

- Wash and dry the limb carefully.
- Manual lymphatic drainage has to be done before bandaging.
- Moisturise with coconut or moistening cream before bandaging.
- Artiflex cotton padding is done to bring the limb into a cylindrical shape.
- Short stretched small, width bandages are applied from the distal to the pommel end of the limb.

### Post bandage assessment

After a bandaging session for lymphedema, it is essential to perform a post-bandaging assessment to evaluate the effectiveness of the treatment and identify any potential issues that may need to be addressed. The post-bandaging assessment typically involves the following steps:

- 1. Measure the limb: Measure the circumference of the affected limb at specific points, such as the ankle, knee, or wrist, to evaluate the degree of swelling reduction achieved by the bandaging.
- 2. Inspect the skin: Inspect the skin for any signs of irritation, redness, or skin breakdown. Any areas of concern should be documented and monitored closely.

- 3. Check for proper fit: Ensure that the bandages are properly applied and do not cause discomfort or constriction. The patient should be asked if they are experiencing any pain or discomfort, and the bandages may need to be adjusted if necessary.
- 4. Evaluate range of motion: Evaluate the patient's range of motion and functional abilities to assess the impact of the bandaging on their mobility.
- 5. Plan for ongoing care: Based on the results of the post-bandaging assessment, the healthcare provider can develop a plan for ongoing lymphedema management, which may include additional bandaging sessions, compression garment therapy, manual lymphatic drainage, or exercise.
- 6. Report to doctors and remove the bandage immediately if any of the following is noted.
  - Pain (pins and needles)
  - Numbness
  - Discoloration of toes and fingers

# Hosiery

Hosiery, also known as compression stockings or compression garments, is a common treatment option for lymphedema. Hosiery is designed to provide graduated compression to the affected limb, which helps to reduce swelling and improve lymphatic flow. Hosiery is easy to use and can be worn during daily activities.

## Indication for hosiery application

- The limb shape is not distorted.
- Mild oedema
- No deep creases
- Skin is tough enough to cope with hosiery.
- No lymphorrhoea

NB: Hosiery is removed at bedtime.



3. Massage: Lymphatic massage is the procedure used to encourage lymphatic fluid away from swollen, congested body areas to areas where it can drain away normally. Lymphedema massage, also known as manual lymphatic drainage (MLD), is a type of massage therapy that is used to help reduce swelling and improve lymphatic flow in individuals with lymphedema. It is a gentle, hands-on technique that uses specific movements to stimulate the lymphatic system and encourage the movement of lymphatic fluid out of the affected area.

# Aim of Massaging

- To stimulate contractions of superficial lymphatics
- To facilitate lymph flow from congested to non-congested areas

## **Contraindications for Massaging**

- Acute cellulitis /erythema
- Renal failure
- Deep Vein Thrombosis
- Unstable hypertension
- Severe cardiac insufficiency
- Hepatic cirrhosis with ascites
- Superior vena cava obstruction

- Untreated tuberculosis or malaria
- When a patient is on active treatment (e.g.: chemotherapy or radiotherapy)

# Techniques

- Keep the patient in a relaxed and comfortable position(lying/sitting)
- While massaging, always clear non-swollen side first to clear the way ahead.
- Use dry hands while performing massage. Cream or powder should not be applied.
- The patient should ideally wear compression garment during massage.
- For head and neck swelling work with nodes at back and front of neck, under chin, occipital nodes, cheeks and lips.
- 4. **Exercise:** Exercise can be a helpful component of a comprehensive lymphedema management plan, as it can help improve lymphatic flow and reduce swelling. However, it is important to approach exercise cautiously and work with a healthcare professional or therapist familiar with lymphedema management to ensure that exercise is safe and appropriate for your individual needs. Exercise reduces soft tissue oedema and improves joint mobility, enhancing the lymphatic pump's efficiency. Wearing a compression bandage during exercise enhances lymph flow and protein reabsorption more efficiently.

# Aim of exercise

- To encourage regular activity e.g., walking
- To prevent stiffness.

# Assessment before exercise

- Posture
- Joint range
- Muscle power
- Function
- Ease of movement.
- Changes in sensation.

# **Exercise for Swollen Arm**

- Patient should be sitting comfortably and arm stretched out at a level with shoulder supported along its length on a pillow.
- The best way to exercise is while wearing a compression garment or bandage.
- Stretch fingers out. Hold for 5 seconds then relax (20 repetitions).
- Make a strong fist. Hold for 5 seconds then relax (20 repetitions).
- Point fingers down towards the floor bending at the wrist. Hold for 5 seconds then relax (20 repetitions).
- Bend hand up pointing fingers towards the ceiling.
- Hold for 5 seconds then relax (20 repetitions).
- Slow circular clockwise and anti- clock-wise movements at wrist joint (20 repetitions each). Stretch fingers out. Raise arm bending at elbow. When arm is fully bent, make a tight fist and twist hand so that palm faces body (supination). Hold for 5 seconds then relax (20 repetitions).

# **Exercise for Swollen Legs**

- These exercises are best done lying on the floor with the legs raised on pillows or cushions.
- Slowly and firmly rotate the feat, making a circular movement with pointed toes.
- Slowly and firmly point your foot towards the floor, then bring it back as far as it will go.

- Slowly and firmly, bring your knees up to the chest.
- Slowly straighten your legs and lower down to the pillows.
- Bring knees up to chest slowly and firmly to do bicycling movements.

## **Health Education**

- Limb elevation is achieved by using 2-3 pillows while lying on the bed.
- Make sure the limb is straight and above the heart level.
- Do not dangle the legs if swollen
- Avoid crossed legs.
- Exercise is to be performed every day, morning and evening.
- Active and passive range of movement exercises.
- A slow and rhythmical rest period must be followed.
- All joints in the affected quadrants will be moved through the pain-free range.
- Exercises are done within the ability of the patient.

# **BLADDER CARE**

Bladder care is an important aspect of palliative care, particularly for patients experiencing symptoms related to urinary dysfunction or who can no longer control their bladder function. Effective bladder care requires a comprehensive approach that addresses the patient's individual needs and goals of care. Here are some key considerations for bladder care in palliative care:

- Assessment: A thorough assessment of the patient's bladder function is essential to develop an appropriate care plan. This may involve evaluating the patient's urine output, assessing for urinary tract infections, and identifying any urinary symptoms such as urgency, frequency, or incontinence.
- **Hydration:** Adequate hydration is important for bladder health and can help prevent urinary tract infections. Patients should be encouraged to drink fluids throughout the day, and healthcare providers may recommend interventions such as IV hydration or subcutaneous hydration if necessary.
- **Incontinence management:** For patients experiencing incontinence, a range of interventions may be used to manage symptoms, including absorbent pads, catheterisation, or medications to reduce bladder spasms.
- **Catheterisation:** Indwelling or intermittent catheterisation may be used to manage urinary retention or incontinence in palliative care patients. Patients and families should be educated about catheter care to prevent infections and other complications.
- **Comfort measures:** For patients who are nearing the end of life, comfort measures may be the primary focus of bladder care. This may involve using absorbent pads or other interventions to manage incontinence and prevent skin breakdown.
- **Family support:** Family members and caregivers may be involved in providing bladder care to palliative care patients. They should be educated about the patient's care plan and provided with the necessary resources and support to manage bladder symptoms effectively.

## Care of urinary catheter

There are several types of urinary catheters used in clinical practice, including:

- 1. **Indwelling catheters:** These are also known as Foley catheters and are the most commonly used type of urinary catheter. They are made of soft, flexible silicone or latex and are inserted through the urethra into the bladder. A small balloon at the end of the catheter is inflated with sterile water to hold the catheter in place. Indwelling catheters are used for longer-term catheterisation and can remain in place for several weeks.
- 2. **Intermittent catheters:** These are also known as in-and-out catheters and are used to empty the bladder intermittently. They are made of silicone or polyurethane and are inserted into the bladder through the urethra. Once the bladder is emptied, the catheter is removed. Intermittent catheters are typically used for short-term catheterisation, such as in patients with urinary retention.
- 3. **Suprapubic catheters:** These are inserted through a small incision in the lower abdomen and into the bladder. They are used when an indwelling catheter cannot be inserted through the urethra, such as in patients with urethral trauma or obstruction. Suprapubic catheters are typically used for longer-term catheterisation.
- 4. **Condom catheters:** These are also known as external catheters and are used in male patients. They consist of a condom-like device that is placed over the penis and attached to a drainage bag. Condom catheters are used for short-term catheterisation, such as in patients with urinary incontinence.

The choice of urinary catheter depends on the patient's individual needs and the duration of catheterisation. Indwelling catheters are generally preferred for long-term catheterisation, while intermittent catheters may be preferred for short-term catheterisation or in patients who require frequent bladder emptying. Suprapubic catheters are used when an indwelling catheter cannot be inserted through the urethra, and condom catheters may be used in male patients with urinary incontinence.

## Care of patient with Urinary Catheter

The nurse plays a crucial role in caring for catheterised patients to ensure their comfort, safety, and overall well-being. Here are some key roles that nurses play in caring for catheterised patients:

- 1. **Catheter insertion and removal**: The nurse may be responsible for inserting or removing the urinary catheter, which requires proper sterile technique to reduce the risk of infection.
- 2. **Monitoring catheter function:** The nurse should monitor the catheter's function to ensure proper drainage and prevent any obstructions, kinking, or dislodgement that may cause discomfort or complications.
- 3. **Managing catheter drainage:** The nurse should monitor the catheter bag's output, color, and consistency to identify any changes that may indicate an underlying condition. They should also ensure the catheter bag is emptied regularly and kept below the level of the bladder to prevent reflux.
- 4. **Preventing infection:** The nurse should follow proper infection control practices when caring for the catheter to prevent urinary tract infections or other complications. They may also administer prophylactic antibiotics or antiseptic solutions as ordered.
- 5. **Providing comfort and support:** The nurse should ensure the patient is comfortable and provide support and education regarding catheter care, including proper hygiene, pain management, and minimising the risk of complications. They should also perform regular assessments to evaluate the patient's urinary system's health and function.

- 6. **Assessing for complications:** The nurse should assess for any signs of complications, such as fever, chills, pain, or bleeding, and report any changes to the healthcare provider promptly.
- 7. **Skin care:** The nurse should perform regular skin assessments to prevent skin breakdown, especially in patients with long-term catheterisation. They should provide appropriate skin care to prevent infection and irritation.
- 8. **Nutrition and hydration:** The nurse should monitor the patient's nutritional and hydration status to prevent dehydration or malnutrition, which may affect the urinary system's function.
- 9. **Bladder training:** The nurse should assess the patient's ability to void, and if possible, initiate bladder training to help the patient regain bladder control and improve their quality of life.
- 10. Education and support: The nurse should provide the patient and their family with education and support regarding catheter care, proper hygiene, pain management, and minimising the risk of complications. The nurse should also help the patient cope with the emotional and psychological effects of long-term catheterisation.

# Health Education

# **Preventing Infection**

- Clean hands before and after touching the catheter or bag.
- Always keep the drainage bag below the bladder level and off the floor.
- Keep the catheter secured to the thigh to prevent it from moving.
- Shower daily to keep the catheter clean.
- The spout of the drainage bag should never touch the side of the toilet or any emptying container.

## **Regular Care**

- 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 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 homecare team if the patient has fever, chills and lower abdominal pain. This could be a sign of a urinary tract infection.

## Don'ts

- Do not lie on or block the flow of urine in the tubing.
- Don't reuse catheters.
- Don't forget to burst a water packet when using hydrophilic catheters.

• Do not let the tube fold or bend.

Don't forget to bring catheter supplies with the patient while travelling

• Instruct the patient and the family caregivers to in- form the homecare team if they notice urinary sediments, peri-catheter pus discharge and cloudy urine. This could be a sign of a urinary tract infection.

Nurse's role in caring for catheterised patients is critical to ensure their safety, comfort, and overall wellbeing. Effective communication with the patient, their family, and the healthcare team is essential to provide coordinated, compassionate care.

# Conclusion

Nurses play an important role in assisting procedures in palliative care. Palliative care focuses on improving the quality of life for patients with serious illnesses by managing symptoms and providing emotional and spiritual support. Their responsibilities include managing pain and other symptoms, providing wound care, providing end-of-life care, and assisting with various procedures as needed. The goal of their role is to provide comfort and support to patients with serious illnesses, as well as their families and loved ones.

# **Activity for Unit 4**

## I. Multiple-Choice Questions

1. What is the best immediate action by the nurse if the patient with colostomy is bleeding from the stoma site while removing the dressing?

- a. Give local compression for 10-15 minutes.
- b. Remove the complete dressing.
- c. Irrigate the wound with saline.
- d. Inform the doctor

## 2. The following action cannot prevent maggots in the wound.

- a. Use mosquito nets.
- b. Maintain personal and environmental hygiene.
- c. Dry dressing
- d. Cover the wound always.

### 3. Bad odour in fungating wounds can be controlled by

- a. Local betadine application
- b. Activated charcoal dressing.
- c. Systemic antibiotics only
- d. Local Hydrogen peroxide dressing
- 4. What type of stool would you expect in the ascending colostomy stoma?
  - a. Liquid stool
  - b. Lose to partly formed stool
  - c. Similar to normal stool
  - d. Semi-solid stool

### 6. The cornerstone of lymphoedema management includes all except

- a. Massaging
- b. Bandaging
- c. Exercise
- d. Adequate nutrition

## 7. Lymphedema is:

- a. A type of cancer in the lymph nodes.
- b. A type of blood clot in the arm or leg.
- c. A build-up of fluids in the tissue
- d. A deficiency of nutrients in the tissues.

8. An unconscious client needs frequent mouth care. When performing mouth care, the best position of a client is:

- a. Fowler's position
- b. Side-lying
- c. Supine
- d. Trendelenburg

## II. True or False

- 1. Putting pressure on the stomal bleeding site is contraindicated.
- 2. The malignant wound does not have a foul odor.

- **3.** An ileostomy is a surgical opening created to bring the large intestine to the surface of the abdomen.
- 4. Tracheostomy patients can clean the inner tube by using a mirror.
- **5.** The inner cannula of the tracheotomy tube should be replaced within 30 minutes to prevent blockage of the outer tube by secretions.

## III. Short notes

- 1. What dietary advice will you give to a patient with a colostomy?
- 2. What are the complications of colostomy?
- 3. What is the other name for the malignant wound?
- 4. Explain the care of the patient with a tracheostomy?
- 5. Explain home teaching for a patient with NG tube

## **IV. Group activity**

**Objectives:** To reinforce the key points while caring for patients with specific conditions. **Activity instruction:** Students will be divided into groups and given a case scenario. They will be instructed to give health education using appropriate AV Aids.

a) Case 1:Mr Kumar, a 49-year-old man had a spinal cord injury in a road traffic accident. His wife is 40 years homemaker with two daughters, 16 and 10. He is on tracheostomy and nasogastric tube feeding and has no bowel and bladder control. He is at his home now.

**Discussion Points:** As a palliative care nurse, provide health education on home care management for Mr Kumar

b) Case II:Mr Joseph, a 65-year-old male has Fungating wound on his cheek (Ca Buccal mucosa), on nasogastric tube feeding. He is complaining of pain and a crawling sensation at the wound.
Discussion Points: As a palliative care nurse, explain the nursing management of this patient.

# OSCE

- 1. Demonstrate catheterisation of a female patient.
- 2. Demonstrate wound dressing.
- 3. Demonstrate tracheostomy care.

# Unit 5 OPTIMIZATION OF CARE

### Introduction

Optimization of care refers to improving the quality of healthcare services and increasing efficiency. Optimization of care in end-of-life care involves ensuring that patients receive the bestpossible care to meet their physical, emotional, social and spiritual needs. This may involve a range of interventions, including pain and symptom management, emotional support, and spiritual care.

### Key aspects of optimization of care

- Communication between patients, families, and healthcare professionals: This may involve discussions about end-of-life care planning, including decisions about life-sustaining treatments, advance directives, and goals of care. By facilitating open and honest communication, healthcare professionals can ensure patients receive care consistent with their wishes and values.
- Use of evidence-based interventions to manage symptoms and improve quality of life: This may involve using medications, such as opioids or other pain relievers, as well as non-pharmacological interventions, such as massage or other forms of complementary therapy. By using evidence-based interventions, healthcare professionals can ensure patientsreceive safe, effective, and appropriate care.
- Addressing the emotional and spiritual needs of patients and their families: This may involve counseling, support groups, or other forms of therapy to help patients and families cope with the challenges of a terminal illness. Chaplains or other spiritual leaders may also be available to provide spiritual support or guidance. Optimization of care also involves providing care that is culturally sensitive and respectful. This may involve understanding and respecting patients' and families' cultural beliefs and practices and incorporating these beliefs into the care plan.
- Patients receive coordinated and integrated care across different settings, such as hospitals, hospices, and home care: By working together as a team, healthcare professionals can ensure that patients receive seamless, high-quality care that meets their needs and preferences. It is crucial to evaluate, acknowledge and optimize the total needs ofpatients with a terminal illness and their families with early, honest and empathetic communication. For caring to happen, we must understand the patients' and their families' needs and priorities. Making individualized shared decisions aiming at "Quality of Life" would be considered an appropriate line of management.

As nurses, we should facilitate to take shared decisions based on discussions with the patientand family. The decisions to be taken are regarding goals of care, emphasizing what is "quality oflife" for them and not what we decide based on organ function. The five priorities focus on: recognizing that someone is dying; communicating sensitively with them and their family;involving them in decisions; supporting them and their family; and creating an individual plan of care that includes adequate nutrition and hydration.

### Essential components of optimization of care

- 1. Quality of life
- 2. Essential care
- 3. Anticipatory prescription
- 4. Dying with dignity
- 5. Care during the terminal phase
- 6. Ethics-based decision making

## 1. Quality of life

**Quality of life** (**QOL**) is defined by the World Health Organization as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. **Quality of life** is the degree to whichan individual is healthy, comfortable, and able to participate in or enjoy life events. Quality of life a broader concept concerned with whether disease or impairment limits a person's ability to fulfila normal role (for example, whether the inability to climb stairs limits a person at work). The feeling of being at peace and having a sense of meaning in life is more important to patients than being active or physical comfort, and spiritual well being.

Quality of life is a dynamic concept that may change throughout illness and treatment. The definition of quality of life is subjective as individuals have very personal descriptions of their concept of quality of life. People also differ in the importance they place on various aspects of illness, which causes a differential impact on the experience of life. Different responses about perceived QOL may be observed even in people with the same clinical condition. Therefore, ensuring the quality of life represents a challenge because cultural, ethnic, religious and other personal values determine how the quality of life is judged.

### 2. Essential care

Essential care in end-of-life care focuses on providing comfort and support to patients as they approach the end of their lives. The goal is to ensure that patients can live their remaining days with dignity and respect and minimize their physical and emotional suffering. Essential care in end-of-life care involves a multidisciplinary team of healthcare professionals, including doctors, nurses, social workers, chaplains, and other specialists. The team works together to provide a rangeof services that address the patient's and their family's physical, emotional, and spiritual needs.



Fig.5.1: NURSE FACILITATING FAMILY MEMBERS TO CARE

**Physical care** is an important aspect of end-of-life care and may involve pain management, symptom control, and other interventions to ensure that the patient is comfortable. Patients may be taking several medications. Essential medications such as anti-hypertensive, hypoglycemic agents, anticoagulants, etc. must be reviewed. Considering the patient's poor food intake, cachexia, and hemodynamic status, except for the essential medications, the rest must be discontinued. Thismay include using medications, such as opioids or other pain relievers, and non-pharmacological interventions, such as massage or other forms of complementary therapy.

**Emotional support** is also a crucial component of end-of-life care. It may involve counselling, support groups, or other forms of therapy to help patients and their families cope with the challenges of a terminal illness. Chaplains or other spiritual leaders may also be available to provide spiritual support or guidance.

**Social support** is also an important aspect of end-of-life care. It may involve connecting patients and their families with community resources, such as hospice services, home care services, or other programs that can provide practical support and assistance.

In summary, essential care in end-of-life care involves a holistic approach that addresses the physical, emotional, and spiritual needs of patients and their families. By providing compassionate and comprehensive care, healthcare professionals can help patients live their remaining days with comfort, dignity, and respect.

### 3. Anticipatory prescription

Anticipatory prescribing is a practice in end-of-life care where medications are prescribed in advance to manage symptoms that may arise as a patient's condition deteriorates. Anticipatory prescribing aims to ensure that patients receive prompt and effective treatment for symptoms without unnecessary delays or discomfort. Anticipatory prescribing enables prompt symptom relief at whatever time the patient develops distressing symptoms. Anticipatory prescribing means

ensuring that someone has access to medicines they will need if they develop uncomfortable symptoms at home or in a care home. The medications are prescribed in advance so that the person can access them as soon as needed.

Although each patient has individual needs, many acute events during the palliative period can be predicted, and management measures put in place. Before discharge from the unit, patient's families must be empowered to manage issues like dyspnea, panic attacks, delirium, pain, extra. A clear discharge summary and medications need to be provided for each symptom. If the familyneeds any assistance linking with local general practitioners to support the family will be helpful.

### 4. Dying with dignity

**Dignified dying:** Dignified dying refers to the process of dying with respect, compassion, and comfort, while maintaining the patient's autonomy and dignity. The goal of dignified dying is to ensure that patients are able to die on their own terms, with their physical, emotional, and spiritual needs addressed in a compassionate and respectful manner. It is a natural death free from avoidable distress and suffering for patients, families and caregivers, following the wishes of patients and families and consistent with clinical, cultural and ethical standards

Key aspects of dignity in end-of-life care are:

- Respect, which includes self-respect, mutual respect, and respect for privacy.
- Autonomy involves having and providing choices, as well as competence and independence.
- Empowerment can involve self-esteem, pride, and modesty.

## 5. Care during the terminal phase

The **terminal phase** is when day-to-day deterioration occurs, particularly of strength, appetite, and awareness. At this phase, nurses must ensure the patient's comfort physically, emotionally, and spiritually and make the end of life peaceful and dignified. We can also make the memory of the dying process as positive as possible for those left behind by our care and support.

**End of Life Care (EOLC)** is the way of caring for a terminally ill patient that shifts attention to symptom control, comfort, dignity, quality of life and quality of dying instead of trying to cure or increase the life.

### **Recognizing the terminal phase**

Remember, these signs and symptoms are very common, but wide variations can occur, so it is

impossible to predict accurately.

- Increasing weakness, the patient becomes bedbound
- Loss of interest in surroundings and food
- Difficulty in swallowing
- Drowsiness
- Cool hands and feet
- Change in breathing (jerky, noisy, very slow, gasping)

## Goals of care

- Explaining and communicating with caregivers so that they are mentally prepared.
  - Find out how much they understand.
  - A person important to them should be present during the discussion.
  - $\circ$  Find out if they wish to know more about the prognosis and discuss it accordingly.
  - o Address their fears and concerns.
  - Provide contact information (ambulance, your contact, nearest doctor, hospital, etc.)
  - Find out if they have any religious, cultural, social or spiritual needs.
  - Explain the uncertainty about the exact time of death.
  - Document the discussion along with the names of the persons discussed.
  - $\circ~$  Discuss the case with the doctor concerned and document it
  - Make the patient as comfortable as possible.
  - Give 'individualized care'.
  - Assess the level of consciousness.
  - Find out the patient's wishes.
  - Record and document preferred place of care (home, hospital, etc.)
  - Find out the wishes of the caregivers.
  - Remember! the wishes and plans may change.

## **Giving Fluid**

If swallowing is difficult, feeding with a spoon is helpful. Ensure that the first sip is swallowed before the next sip.

- Discuss the risk of aspiration.
- Encourage caregivers to give lip and mouth care.
- What the patient can be given depends on the level of consciousness, ability to swallow, and level of thirst.
- Adverse effects of Intravenous fluids
  - Difficult at home
  - o Expensive
  - Needs supervision
  - Infection can occur
  - Fluid can collect in the lungs.

### Review

- All medicines taken by the patient need to be reviewed with the doctor and find out if any 'non-important' medicines can be stopped.
- The doctor will decide on the best route for the medicines.
- Intramuscular and intravenous routes are avoided.
- Subcutaneous injections can be used.
- Regular review is needed.

## Good symptom control

- Provide 'non-drug' methods of symptom control.
- Control of pain: continue pain medicines after discussion with the doctor.
- The patient is likely to pass urine and stool in bed. The caregivers should be taught how to clean the patient.
- After discussion with the caregivers and doctor, catheterization may be needed.
- If the patient cannot swallow, a feeding tube can be inserted after discussion with the doctor and with the consent of the patient and/or caregivers. The caregivers should then be taught how to administer nasogastric feeds.

## Breathlessness

- Consider non-pharmacological methods
  - Switching on the fan
  - Staying with the patient and boosting morale
  - Gently stroking the back
- Do not start oxygen therapy routinely without discussing it with the doctor
- Consider drug therapy (Morphine, alprazolam) after discussing with the doctor and document

### Anxiety, restlessness, and confusion

- Look for causes like pain.
- Ask the doctor for medication.
- Noisy secretions (death rattle) are due to collected secretions at the back of the throat when the patient is too weak to swallow them. They do not cause discomfort to the patient, but relatives may be worried that he is choking or in pain.
- Explain to caregivers that it does not cause distress to the patient.
- Try non-drug measures.
  - $\checkmark$  Place the patient in the recovery position.
  - ✓ Remove the secretion from the angle of the mouth using a finger wrapped in a gauze piece by 'hooking' the finger and 'swiping'.
- Ask the doctor for medication.

### Seizure

- Prevent the patient from self-harm. Do not force any object, like a spoon, into the mouth
- If possible, give intravenous, subcutaneous, or intramuscular Midazolam or any other drug suggested by the doctor.
- Continue anti-epileptics as prescribed.

## Severe bleeding

- Plan for this possibility and discuss it with the family in advance.
- Apply firm and steady pressure wherever possible using dark towels or bed sheets.
- Sedate the patient quickly with intravenous, subcutaneous or intramuscular midazolam or any other drug suggested by the doctor.

## **Supporting the Family**

- The family will be suffering physically, emotionally, socially and spiritually. Hence address these issues and support accordingly.
- Address religious, social and spiritual needs.
- Arrange extra help, including help from a doctor.

The last 48 hours is crucial in caring for the person, family and caring team. There is only one chance to "get it right", and when things do not go well, families and staff can be left with long-term guilt and regrets.

The key to "getting it right" is anticipating that this stage has been reached. Carers who regularly look after the patient and spend the most time with the patient intuitively pick up subtle signs of deterioration. They are often entirely accurate at predicting the approaching death than professionals.

Symptoms	Signs
Profound weakness/bedbound	Gaunt appearance
Needs assistance for basic needs	Drowsiness
Diminished intake of food and fluids	Loss of skin turgor
Disoriented in time, place and person	Dry mouth and conjunctiva
Difficulty in concentrating and cooperating	Cold extremities

# Table 5.1: SYMPTOMS AND SIGNS OF THE DYING PHASE

# **Care of Dying**

Caring for the dying is not only based on scientific principles but it is an art. Unfortunately, the concept is not dealt with due to its importance during the training of nurses. As a result, most traditionally trained nurses cannot provide the necessary care when confronted with dying patients. With adequate training and simple measures, good quality care can be given to these patients and their family members. Providing comprehensive and holistic care will give a sense of satisfaction for the caring team.

## The changes that occur before death

The dying process is unique to each person, but in most cases, there are common characteristics or changes which indicate if a person is dying. Anyone of these signs can be attributed to something other than dying, so remember that the events described here are happening to a personwhose illness is already so severe that life is threatened.

The main changes are:

## **Decreased intake:**

- As a person approaches the End of Life (EOL) phase, the body's nutritional requirement decreases drastically. So, the person may have decreased appetite and decreased thirst.
- It is essential to remember that this is a natural process and not distressing to the patient. But it may be uncomfortable for the family caregivers to see the patient not eating or drinking fluids.
- Reassuring and encouraging them to provide sips of water and applying moist swabs on their lips can promote the patient's comfort. On the other hand, forcing feeds may increase the

patient's distress with little to no benefit.

# Increasing weakness:

- As the person moves closer to death, weakness becomes more and more profound.
- As the weakness increases, general activity decreases.
- Towards the late terminal stage, they may find it challenging to continue conversations and even tolerate personal care.
- The goal at this juncture is to avoid routine care that makes the person uncomfortable and provide care aimed at improving comfort.

## **Increasing drowsiness:**

- As patients drift into the End-of-Life phase, they become increasingly tired, drowsy, and difficult to arouse—the time they spend sleeping increases gradually.
- There may be decreased speech, and they may appear withdrawn.
- In some patients, there may also be confusion, inability to recognize people and restlessness.
- Terminal delirium and restlessness can be effectively managed by Haloperidol or Benzodiazepines based on the cause.
- Family caregivers should be advised to talk to the patient when the patient is fully alert and talk calmly and gently.

# **Changes in respiration:**

- As a person approaches the terminal phase, respiration becomes shallow.
- Some patients' respiratory rate may increase, but respiration usually becomes shallow and spaced out.
- Jaw breathing can be seen in some patients.
- Carers should be reassured that this is a typical dying process that is not distressing to the patient.
- Another distressing symptom for the family carers to watch is the 'death rattle'. It occurs due to salivary secretion and mucus accumulation at the throat as swallowing and coughing reflexes disappear during the end-of-life phase.
- The gurgling sound produced by the oscillating Fluid with each respiration can be distressing to the carers but not the patient.
- It can be managed effectively by turning the patient to the sides and draining the secretions. Anticholinergic like Glycopyrrolate given sublingually or subcutaneously can reduce these secretions.
- The collected secretions should be drained first as these drugs only prevent further accumulation.

# **Temperature:**

- During the terminal stage, the body temperature drops. This may be due to reasons like decreased metabolism and slowing down circulation.
- The feet and hands may appear pale, cold and clammy.
- An extra blanket may be required if the person indicates that they are feeling cold.
- At this point, the room should be well-ventilated and less crowded.

# **Changes in excretion:**

- Urinary and faecal incontinence is observed in only a few patients during end-of-life phase.
- The urinary output decreases drastically; the urine may appear dark and brown.
- There may be oedema due to fluid retention.
- It is vital to keep patients' comfort as apriority at this point.
- Maintaining good perineal hygiene and preventing pressure sores are crucial to maintaining comfort.

## **Nursing Management**

Allow the family to voice their concerns. Clarify expectations and prognosis. Ask the family if they wish to take the patient home or continue terminal care in the hospital.

- Check if appropriate medicines have been ordered for troublesome symptoms, e.g. pain and breathlessness, according to palliative policies and relevant to the care setting (home/ hospital.)
- Check if inappropriate interventions need to be tapered or discontinued.
- Encourage the family to support the primary caregiver and allow them respite.
- Check that nursing care for the patient with attention to oral hygiene and skin, bowel and bladder care is continued.
- Remain sensitive to changes in the patient's and family's physical and emotional needs.

## **Care in the Terminal Phase**

- Allow the family to voice their concerns.
- Clarify expectations and prognosis.
- Involve the Counsellor or Chaplain/ religious representatives like Panditji, Priest, Maulavi oras preferred

## Signs of approaching death

- Facial appearance: Facial muscles relax; cheeks become flaccid, moving in and out with each breath.
- Change in sight, speech and hearing: Sight gradually fails. The pupils fail to react to light. Eyes are sunken and half-closed, and a film appears over the eyes. Speech becomes increasingly difficult, confusing, disoriented, slurred and finally impossible. Hearing is thought to be retained longer.
- Change in the Respiratory System: Respiration becomes irregular, Cheyne stokes, rapid and shallow, or very slow and noisy due to secretions.
- Circulatory system: Pulse becomes slow then stops. There is a fall in BP.
- **Gastrointestinal System**: Nausea, vomiting and abdominal distension are present. The patient may find it difficult to swallow. Patient's appetite gradually decreases, and they stopor refuse to eat and drink. The nurse should not force the patient's family to feed the patient.Offering them ice pops helps them to stay hydrated.
- Skin and Musculoskeletal System: The skin may become pale, cold and clammy. Muscle tone is lost.
- Excretory System: bowel or bladder incontinence or both.
- Central nervous System: Reflexes are gradually lost. The patient may be restless, confused and may have altered sensorium.
- **Hallucinations:** It is not unusual for a dying person to experience hallucinations or distorted visions. It is best not to correct them about these visions, as doing so may cause additional distress. Although this may seem concerning, the nurse can provide reassurance and should explain to the families.

## The psychological needs of a dying person

- Relief from loneliness, fear, and depression.
- Maintenance of security, self-confidence, and dignity.
- Maintenance of hope.
- Meeting the spiritual needs according to his religious customs.

# Care of the dying person

• Provide psychological support to the patient and the near and dear ones. Be warm, supportive and understanding. Do not whisper in the patient's vicinity, which may increase fear.

- Provide privacy, as it will help prevent adverse effects on other patients.
- Need to think about oxygen therapy, IV Fluids and NGT feed, as in palliative care for dying patients, these interventions may not be helpful.
- As the patient may have incontinence, keep him dry and comfortable. The patient can be catheterized. Use pads.
- Provide routine skin care and maintain hygiene.
- If the patient has pain, provide analgesics or other drugs for relief.
- If the patient or relatives desire to perform religious rites, permit them to do so. Depending upon his religious faith, the patient may welcome a visit from a Panditji, Priest, Maulvi or as preferred.

## Care of body after death Diagnosing and declaring death

- Any doctor, preferably from the palliative care unit, can certify death
- Inform the relatives
- Certify death & fill in the necessary forms
- Assist the family in decisions regarding transportation, embalming, mortuary care, etc.

## **Criteria for declaring death**

- Apnea
- Absence of mechanical cardiac activity (absence of heart sounds on auscultation & absence of central pulses on palpation)
- After 5 minutes, check for the following:
  - Absence of pupillary light reflexes (pupils non-reactive to light and fixed)
  - Absence of corneal reflexes (remove contact lenses)
  - Absence of motor response to supraorbital pressure/pain
- If the above features are fulfilled, death can be declared. The time of death should be noted. The record should be signed and dated with the ID number.

### Last office/death care is like any other case in a hospital or homeLast office/death care Purpose:

- To maintain normal body alignment before rigor mortis sets in
- To prepare the body for transport to mortuary/residence
- To reduce mental distress of family

## Articles

A tray with

- Long artery clamp
- Bandage
- Non-absorbent cotton
- Absorbent cotton
- Mortuary card in transparent plastic cover
- Towel
- Hospital gown or patient's clothes draw sheet
- Long mackintosh
- Equipment needed for bath

### Procedure

- If there are oral secretions, turn the patient to the side and drain the secretions.
- Eyes should be closed by applying light pressure for 30 seconds
- Remove all internal devices like urinary catheters, nasogastric tubes and intravenous catheters

and document them in the patient's case sheet. Secure absorbent cotton pads with adhesive tape on the puncture site and wound to prevent leakage and soiling.

- Make the deceased lie supine and straighten all the joints. When rigor mortis sets in, manipulating the joints become difficult; hence all the joints should be straightened early.
- Place a pillow under the head. This keeps the alignment and holds the jaw closed.
- Since the final bath is included as one of the last rites of the deceased, discuss it with the family
- Wash the person's face, gently closing the eyes before beginning, using the soft pad of the fingertip. Close them and hold them in place for a few minutes following death. They may stay closed on their own. If they do not, close them again and place a small soft cotton pad over them.
- Use saline-moistened gauze if corneal or eye donation is likely to take place.
- Clean the mouth and replace dentures after death as soon as possible. Do not remove dentures because you may have difficulty replacing them as the body stiffens. If dentures cannot be replaced, handover to the family in an identified receptacle.
- Keep the jaw closed by placing a towel roll under the chin or preparing a jaw strap with a bandage tied loosely around the head. If the strap is too tight, it can leave pressure marks.
- Tidy the hair and arrange it into the preferred style, if known
- Shaving too soon after death can cause bruising, which may be done later. Explain this to the family if they request shaving. Remember, some faith groups prohibit shaving
- Clear leaking or secretions from the oral cavity or tracheostomy sites by suctioning and positioning, then cover exuding wounds and unhealed surgical incisions with a clean absorbent dressing and secure with an occlusive dressing
- Pack nose and mouth with Non-absorbent cotton using forceps.
- Pack the anus and vagina (if female) with Non-absorbent cotton.
- As the sphincter relaxes, urine and faeces may leak; placing absorbent cotton pads will prevent soiling.
- Clean and dress the deceased person appropriately. Clean the body using a facecloth with water and a small amount of soap. Begin with the arms and legs and then move to the front and backof the trunk. Take assistance from someone to roll the person to each side to wash the back. Fragrant oil may be added to rinse water. Dry one part of the body before moving to another. Some families or cultures may also apply a special lotion, oil or fragrance to the person's skin.
- Dress or cover the body according to personal wishes or cultural practices.
- Remove all valuables in the presence of another staff member and document this. If any jewellery is removed, provide a signature while handing over this to relatives. Document jewellery as yellow metal or white metal and never as gold or silver
- Bring hands over the chest. Interlace fingers and tie the two thumps together with a bandage (or according to their preference).
- Attach one tag to the wrist. Ensure the deceased person is identified with a name band on the wrist.
- Bring the legs together and tie the great toes together.
- Wrap the body with a sheet. Using the clean sheet placed under the patient, wrap the body and secure all limbs within the sheet. Ensure that the feet are also covered, and then cover the face. Apply tape to secure the sheet. Attach the other tag at the center.
- Clear the room of unnecessary clutter and use a clean cloth to cover the patient.
- Cover the prepared body with a sheet and notify the nurse I/c. Call for the messenger to take the body to the mortuary with a copy of the death certificate.

## After Care

• Honour the deceased and their family's religious or cultural wishes/requirements while meeting legal obligations.

- It is essential to give time and space to the family to grieve over their loved one. Offer support to the family through quiet and compassionate presence, active listening and gentle touch.
- Offer support to the family through quiet and compassionate presence, active listening and gentle touch.
- Ensure the deceased privacy and dignity.
- Ensuring the health and safety of everyone who comes into contact with the deceased is protected.
- Replace the articles used for death care.
- Returning the deceased's possessions to the next of kin.
- Screen off the patient's bed area while the removal of the body takes place to avoid causing distress to other patients
- In most hospitals, the body is never handed over to relatives directly. It is always dispatched to the mortuary
- Send the body to the mortuary with a death certificate as soon as possible
- Send information about the death to all concerned
- If the nurse provides death care, document the same
- If there is a risk of infection, a body bag should be used and a hazard labelmust be attached to the body bag and any accompanying documentation. Some hospitals usebody bags for all deceased patients, so follow the hospital policy and SOP of the institution.
- Ensure that the patient's belongings are handed over to the patient's family and document the same.
- Plan for bereavement support visits and document the same in the case sheet

**Documentation:** The nurse should write a detailed report on the death, including the:

- The time
- Who was present/ declared dead
- The nature of the end
- Details of any relevant devices or treatments
- Death care provided by

## Care of unit after death (if in hospital):

- Dispose of used equipment according to hospital policy. Use clinical waste bags to dispose of any waste considered infectious or hazardous. To reduce the risk of cross-infection, wash hands thoroughly and decontaminate hands by using alcohol hand gel
- Terminal disinfection of the unit should be done as per hospital policy

## **DEATH CARE AT HOME**

## What to do in the event of death?

In a clinical setting, a doctor is required to confirm and declare death. Nurses are not authorized to do that. But when death occurs at home, the practice of confirming death differs in different states. It will be prudent to follow the policy of the state when such an event occurs.

## **General guidelines:**

- 1. No matter how much the family is prepared to accept death, it is painful. Giving the family time and space to grieve over their loved one is very important. The first hour after death can be very peaceful. Family can feel sadness and a deep sense of relief, especially if the patient has 'suffered'.
- 2. If possible, encourage the family to have time and space
- 3. Record the time, nature of death, who was present and details of death confirmation in the

patient's case sheet.

- 4. While performing post-death care, discuss patient and family preferences and local cultural practices to be followed.
- 5. Ensure that privacy and dignity are provided to the deceased and the family while providing death care.
- 6. If the family wishes, allow the family to be involved in the deceased's post-death care.
- 7. If the nurse provides death care, document the same in the patient's case sheet.
- 8. Homecare team members should wear appropriate personal protective equipment and follow standard precautions while providing death care. If there is a potential source of infection, advise the family caregivers to wear PPE. (Refer to the chapter on Standard precautions)

## **Bereavement Support for the family**

- Palliative care does not stop with the patient's death. It continues after the patient's death in the form of bereavement support for the family.
- After the death, pay a bereavement visit to the family.
- Collect back any unused opioids and hand them to the palliative team.
- The family may need support for a few months after the death
- People may grieve for six months to one year after death and then slowly resume normal life
- Some people may find it very difficult to accept, especially the death of an earning member or a child and go into depression. They will need a referral to a counsellor or psychiatrist.

## Grief

Grief is the natural response to losing something or someone they hold or feel dear. Bereavement is the state of this loss. It affects a person's physical, social, spiritual and emotional states. Grief as a response to the death of a loved one is to be critically handled. Grief is naturally expressed by mourning (i.e., crying or talking about the loss). Understanding the process of grieving will help us to handle it better. There is no apt process of grieving or reacting to bereavement. It depends on many variables such as personality, nature of the relation, situational conditions and social supports available.

The support for grief should be ideally initiated before death. Any pharmacological intervention cannot suppress grief. A loss of a person with whom we have had a lot of memories will create a void that cannot be filled, leading to a lot of pain. This will be showcased in different ways.

## **Stages of Grief**

**Grieving** is a normal process that usually begins before an anticipated death. The five stages of grief, also known as the Kubler-Ross model, is a widely recognized framework for understanding the emotional and psychological process that individuals may experience after a significant loss. These stages are not necessarily linear, and not everyone experiences them in the same order or at the same intensity. However, they can provide a helpful guide for understanding the grieving process:

- **Denial:** In this stage, the individual may feel disbelief or numbress, and may have difficulty accepting the reality of the loss.
- Anger: As the reality of the loss sets in, the individual may feel angry, frustrated, or resentful. They may lash out at others or at the situation itself.
- **Bargaining:** In this stage, the individual may try to negotiate or make deals with a higher power or with themselves to avoid the reality of the loss.
- **Depression:** This stage involves feelings of sadness, despair, and hopelessness. The individual may withdraw from social interactions and may struggle with daily tasks or routines.

• Acceptance: In this final stage, the individual comes to terms with the reality of the loss and begins to find ways to move forward with their life. This may involve developing a new sense of purpose or finding meaning in the loss.



## Fig.5.2: STAGES OF GRIEF

The grieving process is unique to each individual and can vary depending on factors such as personality, coping style, and cultural background. It is important to note that not everyone goes

through all of these stages, and some individuals may experience additional emotions or reactions that are not included in this framework. If needed, it is also important to seek support from family, friends, or mental health professionals.

In all these stages, the nurse needs to be truthful but prudent in all their dealings with the patient. Maintain a genuine, honest attitude of interest. Be warm, supportive and understanding. The patient may ask many questions and clarify many of his doubts. Let the patient tell you what he knows about his condition. Try to use his own words when talking to him.

### Points to remember:

- It takes time to accept the loss, after which the person undergoes depression and slowly recovers.
- The depression phase can be troubling, and the grieving person can even have suicidal tendencies or feel as if he is going crazy.
- The mere presence of a person would be considerable support for the family. The time required for support may vary considerably from few days to years.
- The foundation for supporting a person in grief is to listen.
- Listening rather than speaking can help the person recover.
- The nurse should motivate the grieving person to talk more about the death, enquiring about their feelings.
- This would help them in accepting the loss and pain of bereavement. Never compare their losses with yours, and avoid remarks or platitudes.
- Major changes in sleeping patterns, considerable differences in weight (loss or gain), feeling confused, inability to concentrate, and inability to stop crying are all associated with grief. If the person recognizes these problems and can talk about them, they will likely be able to recover in time.
- Persistence of these symptoms for more than a few months, suicidal thoughts, thoughts of harming oneself or others, uncontrollable anger, or worries about one's behavior all indicate the need for professional help

## 6. Ethics Based Decision Making

Ethics-based decision making in end-of-life care involves balancing the values and goals of the patient with the ethical principles of healthcare. The goal is to ensure that the patient's wishes

are respected and that care is provided in a way consistent with the patient's values and beliefs. There are several ethical principles that guide decision-making in end-of-life care, including autonomy, beneficence, non-maleficence, and justice. Autonomy refers to the patient's right to make decisions about their care, while beneficence refers to the obligation to do good for the patient. Non-maleficence requires that healthcare providers do no harm, and justice requires that resources be distributed fairly.

In end-of-life care, ethical dilemmas often arise when patients can no longer make decisions for themselves. In these situations, healthcare providers must consider the patient's values and beliefs and the opinions of family members and other caregivers. It may be necessary to consult with a medical ethics committee or seek legal guidance to ensure that the patient's wishes are respected.

One common ethical issue in end-of-life care is the use of life-sustaining treatments such as ventilators and feeding tubes. While these treatments can prolong life, they may also cause discomfort and suffering for the patient. In some cases, it may be appropriate to withhold or withdraw these treatments in order to provide the patient with a more comfortable and peaceful end-of-life experience.

Overall, ethics-based decision making in end-of-life care requires careful consideration of the patient's values and beliefs and the ethical principles that guide healthcare practice. By balancing these factors, healthcare providers can ensure that end-of-life care is provided in a respectful, compassionate way, and in line with the patient's wishes.

### The foundation of medical ethics is supported by the four pillars, namely;

- 1. Autonomy- Patient has the right to choose or refuse a particular treatment. In the event the patient has diminished decision-making capacity, surrogates acting on the patient's behalf can communicate the patient's previously expressed wishes.
- 2. **Beneficence-** The doctor should act in the best interest of the patient. In the context of an advanced progressive illness with no scope for reversal, the patient's best interests are controlling the patient's pain and symptoms, reducing the sufferings of the patient and his family, providing emotional support and protecting the family from financial ruin.
- 3. Non-Maleficence- Do no harm to the patient. Thus, withholding and withdrawing the life support, in this context, is a humane approach to 'allowing natural death,' that is, allowing the patient to die of the underlying illness, with symptoms well–controlled, in a dignified manner, in the presence of his family and loved ones and this in no way amounts to euthanasia.
- 4. Justice- Equitable distribution of service and equal right to care for all patients.



**Fig.5.3: PILLARS OF MEDICAL ETHICS** 

Added to the above four are two more aspects which form the cornerstones of medical practice:

- 1. **Dignity** the patient and the persons treating the patient have the right to dignity
- 2. Truthfulness and honesty the concept of informed consent and truth-telling should be engrained in the practice of end-of-life care.

## Thus, it is crucial to integrate the ethical principles in the practice of palliative care and endof-life care in the background of cultural and social influence. End-of-life care must be embedded in the ethical principles of palliative care.

Palliative care is important in advanced health-related suffering and life-limiting illnesses. The different aspects of palliative care, such as pain and symptom control, psychosocial care, and endof-life issues, should be managed ethically. The cardinal ethical principles to be followed are autonomy, beneficence, non-maleficence and justice.

- The palliative care experts and team members should carry out their responsibilities with honesty and dignity.
- Suffering due to unrelieved pain and unavailability of Morphine are recognized as negligence of human rights.
- There are practical ethical challenges which need to be resolved. Truth-telling, place of care, • continuity of effective palliative care till the last days of life, confidentiality, use of antibiotics and blood transfusion, nutrition and advance directives can be the key points which confront a palliative care team.
- Progress in palliative care will come out of good research and medical professionals should • undertake trials and studies in a legal and ethical manner.
- The delivery of palliative care and medical ethics are complementary, and use of the two • together maximizes the protection and satisfaction available to the vulnerable patient and family members.
- Decisions are made on the grounds of benefits/burdens proportionality. To justify a particular • intervention, the expected benefits of that intervention must outweigh the burdens. Burdens might include intractable pain, disability, emotional suffering or other factors which seriously compromise the patient's quality of life. Treatments considered reasonable in the early stages of illness when the patient is enjoying a good quality of life may be seen as unreasonable later in the illness. Furthermore, each intervention should be individually subjected to this consideration. For example, a patient who is not expected to benefit from ventilation may be helped symptomatically by administering oxygen. Importantly, the withholding or withdrawal of life-sustaining interventions should never mean the withdrawal of care. Adequate symptom control and emotional and spiritual support for the patient and family must be ensured.

### **Collective decision making**

Dying is a very special and unique event for each individual. In palliative care approach exploring the patient's wishes about death and dying should be done in the beginning itself. Relatives need to be involved and patient's wishes would need to be balanced with the palliative care team's views. Most patients wanted to be at home during the lost weeks or days around the relatives. Relatives should determine who and how the body is dealt with after death. This is an important part of their last 'duty'. It is important to be sensitive to the cultural and religious beliefs because different religious and cultural groups have different approaches the dying processes.

### **Role of palliative care nurse**

• Coordinate with the other health care members and facilitate a death that's as dignified and comfortable as much as possible and that honours the patient's and family's wishes.

- Provide a culturally sensitive, practical, and timely interventions that reduce physical, emotional, and spiritual suffering.
- Provide ongoing education to the patient and family members, who may have had little experience with death and may not understand the dying process.
- Provide information about the patient's condition, discuss the risks and benefits of medical treatments, and answer family members' questions about care options for their loved one.
- Guide the discussion and address the questions but do not dictate what decisions the patient and family should make.
- Nurses must understand that the death approaches, the patient's comfort and the patient's and family's emotional and spiritual well-being and take precedence over clinical priorities.
- Provide reassurance and physical presence are critical at this time to ease the patient's and family's fear and loneliness and to facilitate the transition.
- Discuss patient preferences about withholding hydration and nutrition, the timing for discontinuing treatments, and the selection of a surrogate decision maker.
- Adjust the temperature and lighting in the room, as needed
- Observe for signs of terminal delirium, such as a decreased level of consciousness or unresponsiveness, confusion, disorientation, hallucinations, agitation, or restlessness.
- Note that agitation is common in the final hours of life and may be due to the effects of medications, changes in metabolic status, organ failure, faecal impaction, bladder distention, hypoxia, and unresolved emotional or spiritual issues.
- If the patient is experiencing agitated delirium, collaborate with the interdisciplinary team to identify and treat reversible causes if possible, such as discontinuing unnecessary medications.
- Administer Haloperidol or another antipsychotic agent as prescribed following safe medication administration practices.
- Treat the patient's pain using non-pharmacologic, pharmacologic, or a combination of approaches.
- Don't abruptly discontinue opioid pain medication, even if the patient is unresponsive.
- Although a hypoxemic patient may benefit from supplemental oxygen, it isn't routinely used for air hunger at the end of life.
- If the patient can't clear secretions, reposition the patient and elevate the patient's upper body and head. Administer an anticholinergic or antispasmodic, as appropriate and as needed and prescribed, following safe medication administration practices *to dry secretions*.
- Note that sounds made by the patient with excessive secretions are often more distressing to family members than to the patient.
- If the patient is experiencing nausea, collaborate with the interdisciplinary team to identify and treat reversible causes if possible. Administer anti-emetics, as needed and prescribed, following safe medication administration practices. Provide non-pharmacologic interventions, such as limiting movement and removing noxious odors, as appropriate.
- Assess the patient for the effects of dehydration, such fatigue, dizziness, headache, dry mouth or eyes, scant or dark-colored urine, and muscle cramps,
- Offer (but don't force) oral fluids if the patient can still swallow. Administer artificial hydration if ordered and consistent with the patient's care goals. Advise the patient and family that administering fluids via the enteral or parenteral route doesn't reverse the underlying disease process or significantly increase survival and may contribute to the physiologic burden of dying.
- Although increasing oral intake is the preferred method of providing fluids, especially in the home environment, artificial hydration via the IV, subcutaneous (hypodermoclysis), or rectal (proctoclysis) route may be considered in some patients if the potential benefits, such as increased alertness and reduced myoclonus, outweigh the potential risks related to fluid

retention, such as edema, nausea, pain, and dyspnea.

- Provide oral care, taking care to moisturize the patient's oral mucosa and lips as needed, *to prevent or relieve discomfort*.
- Lubricate the patient's eyes with an ophthalmic solution (such as artificial tears) or ointment, as needed and ordered, *to prevent or relieve discomfort*.
- Assess the patient's skin for temperature, moisture, color, and breakdown. Note that as peripheral circulation decreases and death approaches, the skin is typically cool and moist and becomes mottled, especially on the soles of the feet and over bony prominences. Skin darkens in dependent areas, such as the sacrum (when the patient is supine), as blood pools in these areas.
- Reposition the patient as tolerated, change the patient's clothing and linens when soiled or moist, and provide skin and wound care as indicated. (See the "Wound palliative care, home care" procedure.) Make sure that the linens cover the patient loosely *to reduce discomfort caused by pressure from the linen*.
- Assess the patient for urinary and bowel incontinence, which can occur as the patient's sphincters relax as death approaches.
- Change fluid-impermeable pads and provide perineal care, as needed. If the patient is incontinent of urine and can't tolerate repositioning and perineal care, insert an indwelling urinary catheter (if ordered) *to promote comfort*.
- Encourage family members to participate in the patient's care and teach them how to provide comfort measures to the patient, such as positioning, mouth care, skin care, and gentle massage.
- Teach the patient and family members to use non-pharmacologic strategies, such as relaxation techniques, guided imagery, and distraction, to ease symptoms (such as discomfort, nausea, anxiety, depression, and fatigue) that may be present at the end of life. If the patient and family are interested in using complementary therapies (such as music therapy, massage therapy, and aromatherapy) to control symptoms, notify the patient's practitioner for appropriate orders and referrals.
- Reassess and respond to the patient's pain by evaluating the response to treatment and progress toward pain management goals. Assess for adverse reactions and risk factors for adverse events that may result from treatment.
- Provide the family with anticipatory guidance on the signs of impending death.
- Support the patient and family in expressing cultural, spiritual, or religious traditions related to the end of life. Encourage the family to provide objects that comfort the patient, such as religious items or photographs.
- Allow the patient and family to express their feelings, which may include acceptance, anxiety, denial, disappointment, loneliness, regret, resentment, and sadness. Actively listen without rushing them, and display empathy. Acknowledge their feelings and provide emotional support.
- Encourage the patient and family to reminisce and appropriately express affection. Remain present or provide privacy according to their wishes
- Ask the patient and family about organ and tissue donation when appropriate. Explain the process or, if the patient has already registered to become a donor, verify the registration in the patient's medical record. Contact a regional organ procurement organization for specific
organ and tissue donation criteria.

- Review progress toward the goals in the patient's plan of care with the patient and family as appropriate.
- Make arrangements for the next visit as appropriate and ensure the patient and family members have adequate supplies for caring for the patient themselves until then.
- Provide and review written educational materials, the visit schedule, and contact information should concerns arise between visits.

### Conclusion

Living with a life-limiting illness and awareness of approaching death creates unique stressors and new challenges. Patients and families must manage the new demands associated with the illness while maintaining the quality of life and meaning within their relationships. By optimizing the care, we should ensure that the suffering is minimal and symptoms are managed, the family has closure, unfinished issues are resolved, dignity is preserved, feelings of being loved and valued are addressed, a peaceful atmosphere is achieved, and a supportive presence is provided.

The end-of-life decision must begin at the point of diagnosis of advanced, progressive or metastatic cancer when the primary team is certain that the disease-modifying treatment or intensive medical management will not benefit the patient or lead to health deterioration. Once the primary treating team recognizes the medical inappropriateness of a particular treatment; they could call upon the other teams involved in caring for the patient and the palliative care team and discuss all the possible options for correcting the reversible cause. If the team members have reached a consensus of saturating all the options, they could then call upon a meeting with the patient and the family members.

# **Activity for Unit 5**

### I. Short Answer

- 1. What are the signs and symptoms of impending death?
- 2. What is dignified dying?
- 3. Explain the criteria for confirming death.
- 4. Explain principles of medical ethics in palliative care.

### II. Observation Visit Report to hospice/ palliative care unit

After visiting the palliative care unit/hospice the students should submit a visit report incorporating the following aspects:

- a) Describe the geographical location.
- b) Sketch the physical lay out.
- c) Identify the services provided, multidisciplinary team, the available facilities, strength and weakness of the unit.
- d) Describe the daily routine for patients in the unit.
- e) Explain about the assessment of pain and symptom management.
- f) Enumerate the and resources and facilities available to patients and their families
- g) Discuss the training provided to caregivers.
- h) Explain the in- service/ staff development programmes available.
- i) Identify end-of-life care and bereavement support provided to the patients and families.
- j) Discuss the tools used to measure quality of life for patients in the unit.

# Annexure

# 1. Support Resources to enhance learning.

Videos can be a great tool to enhance learning, as they can provide a visual and auditory experience that can help engage learners and increase retention. Training videos can be an effective tool for healthcare professionals to learn about palliative care and improve their skills in this area. Hindi versions are also available in YouTube for the following videos. Here are some recommended training videos in palliative care:

#### Communication

- 1) How to not communicate with Palliative Care Patients | Palliative Skill Videos (English)https://www.youtube.com/watch?v=TYRbdP9eTng
- 2) How to Communicate Effectively with Palliative Care Patients | Palliative Care (English)https://www.youtube.com/watch?v=n7Zn5QUaC5s

#### **Nursing Procedures**

- 3) How To Make Bed For Palliative Care Patients | Palliative Care (English)https://www.youtube.com/watch?v=gbKn8oMVpDI
- 4) How to Maintain Oral Care in Conscious Patients | Palliative Care (English)https://www.youtube.com/watch?v=gZVUBQVoyrI
- 5) How to Maintain Oral Care In Unconscious Patients | Palliative Care (English)https://www.youtube.com/watch?v=BfYvfy97D0Y
- 6) Prevention of Bed Sore || Palliative Care (English)https://www.youtube.com/watch?v=55aJnhJRwT0&t=194s
- 7) Hair care in Palliative care (English)- https://www.youtube.com/watch?v=FQsAZNgYmmY
- 8) Nail care in Palliative care (English)- https://www.youtube.com/watch?v=YYSgHAbuCkw
- 9) Steps to undertake catheterization in Male | Palliative Care (English)https://www.youtube.com/watch?v= hsqTXbsjhs
- 10) Steps To Insert Nasogastric Tube | Palliative Care (English)https://www.youtube.com/watch?v=7Vzf4jMdrvI
- 11) How to feed through Nasogastric tube | Palliative care (English)https://www.youtube.com/watch?v=44mJ9VUsGHM
- 12) Catheter Care Procedure for females | Palliative care (English)https://www.youtube.com/watch?v=3IAcHNEMaLQ
- 13) Procedure of Catheter Care for Males | Palliative care (English)https://www.youtube.com/watch?v=690Dll-R-h8
- 14) Steps to undertake catheterization in Male | Palliative Care (English)https://www.youtube.com/watch?v=\_hsqTXbsjhs
- 15) How to Clean the Private parts of a female patient in Palliative care (English)https://www.youtube.com/watch?v=UgCadDBakCU
- 16) How to Clean the Private parts of a Male patient | Palliative care (English)https://www.youtube.com/watch?v=UyPpn20d8Ug
- 17) How to infuse subcutaneous fluids into a patient (English)https://www.youtube.com/watch?v=Mt31T7UKDIU

# 2. Sample Evaluation

At the end of the training program, the candidates will be evaluated based on objective type questions. Minimum 50% marks to be secured for completion of the training and certification.

### Scheme of evaluation:

**Duration:** 45 minutes **Question pattern:** Multiple choice questions -15 X1 = 15

True or False -10 X1 = 10

Total Marks – 25

# **Model Question Paper**

#### Test your Knowledge:

- 1. All of the following statements about palliative care are true EXCEPT:
  - a) Palliative care can lead to significant improvement in a patient's quality of life
  - b) Palliative care can alter the clinical outcome.
  - c) Palliative care is always more expensive
  - d) Palliative care accepts dying/death as a normal process
- 2. All of the following patients are eligible for palliative care EXCEPT:
  - a) A 65-year-old man with two broken legs but he is otherwise healthy
  - b) A 27-year-old woman with end-stage hepatitis C and AIDS
  - c) A 70-year-old man with metastatic cancer and a very poor prognosis
  - d) A 94-year-old woman with end-stage renal disease
- 3. Choose the correct answer from the options given below. When should palliativecare begin?
  - a) After completing curative treatment
  - b) After all, treatments have failed
  - c) From the time of diagnosis of chronic illness
  - d) When the disease reaches terminal stages
- 4. All of the following statements about palliative care are true EXCEPT:
  - a) Physicians, nurses and physical therapists are often part of a palliative are team
  - b) Patients cannot receive palliative care if they are receiving curativetreatments
  - c) Palliative care team members address symptoms such as insomnia, anorexia and delirium
  - d) Palliative care team members often provide emotional support
- 5. Which of the below is an example of good communication skill?
  - a) Interrupting
  - b) Changing the topics to physical concerns
  - c) Silence
  - d) Looking away
- 6. Treatment decisions are to be made by:
  - a) Patient alone
  - b) Doctor alone
  - c) Patient empowered with information
  - d) Senior relatives and the doctor

- 7. Which of the following healthcare set up can provide palliative care services?
  - a) Tertiary care hospital
  - b) hospice
  - c) Home-based care programs
  - d) All the above
- 8. Principles of palliative care are:
  - a) Providing adequate analgesic, disease management, and place to die
  - b) Psychosocial care, symptom control, & disease management
  - c) Religious /spiritual support and psycho social care
  - d) Disease management, intensive care & symptom control
- 9. What is the aim of rehabilitation in community-based palliative care?
  - a) To make the patient attain complete physical fitness
  - b) To make the patient fit enough to attend hospital services
  - c) To help patients maximize opportunity, control, independence and dignity.
  - d) To help patient achieve the functional capacity he/she had before the disease

10. Which of the following is an example of an 'open-ended question'?

- a) How is your pain today?
- b) Your pain is better today. Isn't it?
- c) How much has your pain decreased with the injection?
- d) All of the above
- 11. Which is the ideal way to overcome denial?
  - a) Be short and precise
  - b) Involve colleagues as a testimonial
  - c) A non- confrontational approach
  - d) Rational and assertive explanation
- 12. Breaking bad news in a seriously ill patient:
  - a) Destroys hope completely
  - b) Hastens death
  - c) Fosters appropriate hope
  - d) Disturbs treatment plans
- 13. Management of G I symptoms include:
  - a) The anticipation of problems before they occur
  - b) Ongoing assessment of treatment and their effectiveness
  - c) Reassess the treatment
  - d) All of the above
- 14. Mouth care should be undertaken in all patients:
  - a) Once in the morning
  - b) 2-4 hours
  - c) 6-8 hours
  - d) On request by the family

- 15. Which is not a feature of oral candidiasis?
  - a) Intense inflammation
  - b) The reddish appearance of the mucosa
  - c) White patches in the mucous membrane
  - d) Leukoplakia
- 16. Management options for candidiasis:
  - a) Antibiotic
  - b) Antiviral
  - c) Antifungal
  - d) Hormone Therapy
- 17. All of these drugs are used for opioid-induced constipation EXCEPT:
  - a) Stimulants
  - b) Faecal softeners
  - c) Rectal agents
  - d) Bulk-forming agents
- 18. Commonest causes of diarrhea in the palliative care setting is:
  - a) Malabsorption
  - b) Bowel fistulae
  - c) Odd dietary habits
  - d) Imbalance of laxative therapy
- 19. The most common side effect of Morphine is:
  - a) Nausea
  - b) Sedation
  - c) Constipation
  - d) Itching
- 20. Which among the following drugs belong to Step III of WHO analgesic ladder?
  - a) Morphine
  - b) Diclofenac
  - c) Codeine
  - d) Paracetamol
- 21. Which of the following is NOT a side effect of oral Morphine?
  - a) Constipation
  - b) Nausea
  - c) Urinary hesitancy
  - d) Respiratory depression
- 22. Which among the following is **<u>not</u>** an input ostomy?
  - a) Colostomy
  - b) Gastrostomy
  - c) Jejunostomy
  - d) Tracheostomy

- 23. Eye care in an unconscious patient include the following Except:
  - a) cleaning from inner to outer canthus
  - b) cleaning from outer to inner canthus
  - c) using separate swabs for both eyes
  - d) keep the eyelids closed to prevent corneal ulcers
- 24. The major problem in a bed ridden patient:
  - a) Corneal ulcer
  - b) Pressure sore
  - c) Malnutrition
  - d) All of the above
- 25. How many steps are there in the WHO analgesic ladder for cancer pain?
  - a) 2 Steps
  - b) 3 Steps
  - c) 4 Steps
  - d) 5 Steps

#### 26. Which of the following side effect is associated with Opioid administration?

- a) Agitation
- b) Constipation
- c) Lethargy
- d) Nausea
- 27. Which one is the primary aim of palliative care?
  - a) Mercy killing
  - b) Todelay death
  - c) To make life as comfortable and as meaningful as possible
  - d) To prolong life
- 28. Why is there a need for Palliative Care in older people?
  - a. There is a higher incidence of injury amongst older people.
  - b. Older people suffer from chronic illnesses.
  - c. Older people have multiple concerns at physical, emotional and social dimensions.
  - d. All of the above.
- 29. Regarding elderly patients choose the wrong statement:
  - a. Anxiety and adjustment disorders common.
  - b. The best place for the elderly to be cared is in their homes.
  - c. Depression is not common.
  - d. Impairment of memory and cognition are problems in the aged.
- 30. The solution of choice to remove maggot:
  - a) Betadine
  - b) Turpentine
  - c) Normal saline
  - d) Hydrogen peroxide

- 31. Which of the following methods are used for controlling bleeding from awound?
  - a) Local pressure
  - b) Adrenaline pack
  - c) Local application of Sucralfate
  - d) All of the above

#### 32. The food that can cause malodor in colostomy patient:

- a) Egg
- b) Cabbage
- c) Onion
- d) All the above
- 33. The following should be avoided in arm affected with lymphoedema:
  - a) Tight clothes
  - b) Injection
  - c) Checking BP
  - d) All the above
- 34. The following should be done during massage for lymphoedema limb EXCEPT:
  - a) Deep massage
  - b) Direction of massage should be towards heart
  - c) Superficial massage
  - d) Starting from normal area to the affected side
- 35. The following are corner stones of ethics EXCEPT
  - a) Honesty
  - b) Autonomy
  - c) Justice
  - d) Beneficence
- 36. Care of a dying patient should be:
  - a) By a team approach
  - b) Always in the hospital
  - c) By a family and friends alone
  - d) A doctor alone
- 37. The following drugs should be continued in a dying patients EXCEPT:
  - a) Analgesics
  - b) Anticonvulsants
  - c) Antiemetics
  - d) Oral hypoglycemic agents
- 38. What are the ways of helping a bereaved Person?
  - a) Non-judgmental listening
  - b) Providing information
  - c) Becoming familiar with own feelings
  - d) All

- 39. A patient's fear to take opioids might be related to a belief that:
  - a) the side effects of opioids cannot be managed.
  - b) the increase of pain signifies that the disease is getting worse.
  - c) if he or she takes strong drugs now, no drugs will be effective in the future.
  - d) All of the above
- 40. Which of the following is the most reliable indicator of pain?
  - a) Patients' self-report
  - b) Results of physical examination
  - c) Results of functional assessment
  - d) Results of multidimensional assessment

#### Answers

Qn. No	Answer						
1.	С	11.	С	21.	С	31.	D
2.	Α	12.	С	22.	Α	32.	D
3.	С	13.	D	23.	В	33.	D
4.	В	14.	С	24.	D	34.	Α
5.	С	15.	Α	25.	В	35.	Α
6.	С	16.	С	26.	В	36.	Α
7.	D	17.	D	27.	С	37.	D
8.	В	18.	D	28.	D	38.	D
9.	С	19.	С	29.	С	39.	D
10.	Α	20.	Α	30.	B	40.	Α

# True (T) or False (F)

1.	Palliative care uses a team approach				
2.	Palliative care is synonymous with terminal care				
3.	Palliative care includes the family in the care process				
4.	The need for Palliative care inputs are the same throughout the disease trajectory				
5.	The Founder of palliative medicine is Florence Nightingale	F			
6.	Palliative care focuses on the whole person				
7.	Palliative care cannot be practiced in conjunction with other therapies				
8.	Palliative care is only for patients with malignant diseases.				
9.	Palliative care is care given only during terminal stages of the disease	F			
10.	The support provided to the family after the death of the patient iscalled bereavement support.	Т			
11.	Silence is a means of communicating	Т			
12.	Withholding bad news from the patients helps him cope better.	F			
13.	Withholding bad news from the patient (or) their relatives is calleddenial	F			
14.	Breaking bad news must be completed in a single interview	F			
15.	Every patient has to be told details of their diagnosis and prognosis	Т			
16.	Collusion makes the work for doctors easy and quick	F			
17.	Sensitive truth-telling is harmful to patients.	F			
18.	Nurses can show emotions even at the clinic; it is helpful forpatients.	Т			
19.	Nursing students need to be trained in good communication skills	Т			
20.	Spirituality and religion are different	Т			
21.	Pain which is associated with tissue distortion (or) injury is calledneuropathic pain.	F			
22.	Assessment of a patients pain should be done objectively	Т			
23.	Most of the patients with advanced cancer have more than onepain	Т			
24.	Cleaning is done from a clean area to a less clean area.	Т			
25.	Dressing must be soaked before removal to reduce pain andbleeding from the wound	Т			
26.	A laxative should be routinely prescribed while starting a strongopioid	Т			
27.	The most expected side effect of oral Morphine is diarrhea.	F			
28.	Whole-body should be exposed and bathed at the time of givinga bed bath	F			
29.	Soaps which contain less alkali should be used for bed bath	Т			
30.	Good hair care enhances self-image of the patient	Т			
31.	Tap water is used for bowel irrigation in patients with colostomy	Т			
32.	Patients should be advised not to travel with the colostomy bag	F			

33.	Putting charcoal in the colostomy will reduce malodour				
34.	The outer tube of tracheostomy should be cleaned and boiledevery day.				
35.	Tracheostomy patients can be trained to speak.				
36.	Blood pressure should not be checked on the lymphoedema arm				
37.	Compression bandage promotes lymph flow				
38.	Exercise should be strictly avoided in lymphoedema limb	F			
39.	It is always good to predict prognosis when the patient is in the terminal phase.	Т			
40.	Profound weakness in a patient with advanced disease can be asymptom of death.	Т			
41.	Views of the family and friends on the care of the patient areessential in the case of a terminal illness.	Т			
42.	The patient should always be encouraged to die in the hospital.	F			
43.	Non humidified Oxygen therapy causes xerostomia	Т			
44.	Grief is an abnormal reaction to a death.	F			
45.	In palliative care setting Morphine is be used for the treatment ofbreathlessness	Т			
		1			

# 3. Courses for Nurses offered at Pallium India

**Pallium India offers courses and training programs for nurses** to develop the knowledge and skills necessary to provide high-quality palliative care services. An activity session is added to enhance students learning at the end of each unit.

Pallium India offers a range of courses and training programs specifically designed for nurses who wish to specialize in palliative care. Some of these courses include:

- 1. Certificate Course in Palliative Care Nursing (CCPCN): This sixweek course covers thebasics of palliative care nursing. The course is designed to provide nurses with the knowledge and skills needed to care for patients with life-limiting illnesses.
- 2. Certificate Course in Palliative Care Nursing for Pediatric Oncology (CCPCNP): This six-week course is designed for nurses who wish to specialize in pediatric palliative care. The course covers the unique needs of children with cancer and other life-limiting illnesses.
- 3. The Foundation Course in Palliative Care: It is a short-term course offered by Pallium India designed to provide healthcare professionals an introduction to the basics of palliative care. The course is delivered through a combination of online lectures, case discussions, and interactive sessions with faculty members.
- 4. The online course 'Essentials of Palliative Care India' is designed to allow self study. This course allows nurses to understand the essentials of palliative care, pain management, communication skills and symptom management.

Nurses interested in undertaking courses in palliative care can visit the website (<u>https://palliumindia.org/training</u>) to know more about upcoming training. Pallium India is an NGO based out of Trivandrum that strives to alleviate health-related suffering. Pallium India demonstrates educates and facilitates the integration of palliative care into mainstream healthcare.

# Reference

#### The module is compiled from,

- 1) Handbook for Health Care Workers, National Programme for Palliative Care, Government of India.
- 2) Training Manual on Palliative Care for Staff Nurses at Ayushman Bharat- Health and Wellness Centers
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- 4) Home-Based Palliative Care A Manual for Nurses, WHOCC for Community Participation in Palliative Care and Long Term Care, 2020
- 5) Palliative Care, A Handbook for Nurses A Handbook for Nurses, Stella Timung, RN, Institute of Palliative Medicine
- 6) Operational Guidelines for Palliative Care at Health and Wellness Centers, NHSRC.
- 7) Induction Training Module for Community Health Officers, National Health Systems Resource Centre (NHSRC)
- 8) Handbook for Certificate Course in Essentials of Palliative Care, Indian Association of Palliative Care, Fifth Edition, 2017
- 9) Planning and implementing palliative care services: a guide for programme managers, World Health Organization, 2016
- Guidelines for Stocking and Dispensing Essential Narcotic Drugs in Medical Institutions, Compile by Nandini Vallath, M R Rajagopal, Tripti Tandon, NCG Palliative Care Committee, 2017