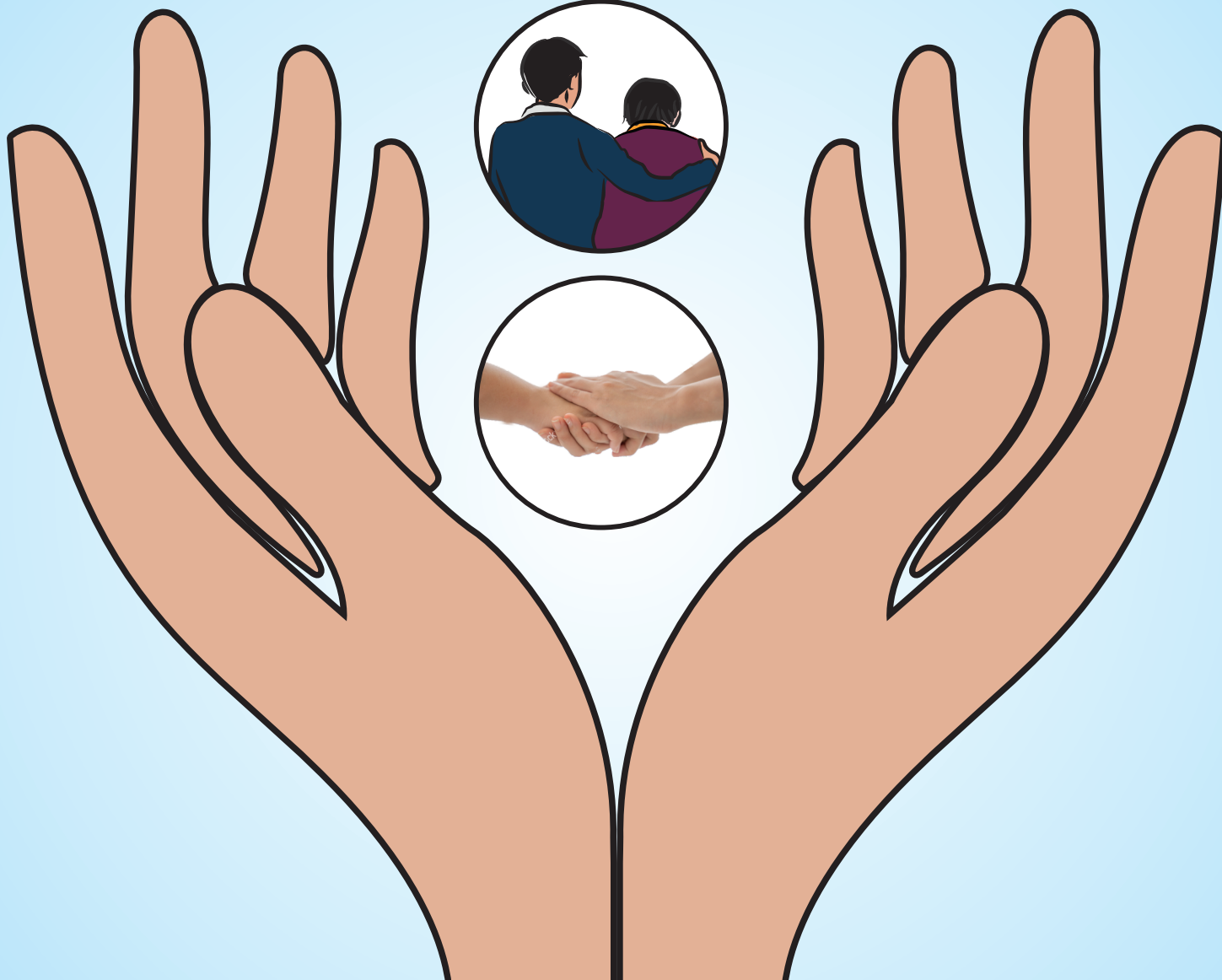




सत्यमेव जयते

Ministry of Health & Family Welfare  
Government of India



## Training Manual on Palliative Care for Community Health Officer at Ayushman Bharat – Health and Wellness Centres





## PREAMBLE

With the National Health Policy of 2017, India took a giant step towards a Healthier India.

Health is defined as “a state of complete physical, social and mental well-being and not merely the absence of disease or infirmity.”

The conventional health care system concentrates on prevention, diagnosis and cure of diseases. Unfortunately, this often leaves suffering unattended. It is estimated that at least 10 million Indians are in serious health-related suffering every year.

The suffering can be because of pain and other symptoms or because of social, mental or spiritual issues. Palliative care addresses serious health-related suffering in all these domains. Understandably, dealing with these necessitates are multidisciplinary teamwork. There is something for everyone to do, including the patient and family, the community around them and all participants in health care delivery.

If we are to prevent and treat suffering, the application of palliative care has to happen all through the course of the disease from the time the suffering starts, which can even be before the time of diagnosis. Wherever disease-specific treatment is being given, it has to go hand-in-hand with palliative care.

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.

This training program is aimed at empowering every health care provider to be a partner in reducing health-related suffering in our country.





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## **Definition of terms**

### **Acronyms and Abbreviations**

- AIDS -Acquired Immunodeficiency Syndrome
- ANM- Auxiliary Nurse-Midwives
- AWC -Anganwadi Centre
- AWW- Anganwadi Worker
- CBAC- Community Based Assessment Checklist
- CHC -Community Health Centre
- CHO- Community Health Officer
- CPHC- Comprehensive Primary Health Care
- DH- District Hospital
- FRU- First Referral Unit
- HIV- Human Immunodeficiency Virus
- HWC- Health and Wellness Centres
- IAPC – Indian Association of Palliative Care
- ISSP – Indian Society for Study of Pain
- MCI – Medical Council of India
- MLHP Mid-Level Health Provider
- MoHFW – Ministry of Health and Family Welfare
- MPW- Multi-Purpose Worker
- NACO – National AIDS Control Organization
- NCD – Non-communicable Diseases
- NCD Non-Communicable Disease
- NDPS Act/Rules – Narcotics & Psychotropic Substances Act/Rules
- NGO – Non-Governmental Organization.
- NPCDCS – National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke
- PC- Palliative Care
- PHC- Primary Health Centre
- PLHIV- People Living With HIV/AIDS
- PLHA -People Living with HIV/AIDS.
- PSG- Patient Support Group
- RMI - Recognized Medical Institution
- SHG- Self Help Groups
- STI- Sexually Transmitted Infections

## Chapter 1:

# Introduction to Palliative Care

### Learning Objective

At the end of the session, you should be able to:

- Define palliative care
- Describe the brief history of palliative care
- Describe the concepts of palliative care as part of a continuum of care
- Describe the concepts of a holistic approach to care
- Describe the models of palliative care provision

### Group- activity

A 50-year-old woman with advanced ovarian cancer is in your neighbourhood. She has two daughters aged 24 and 16. 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 the body, and she looked apprehensive.

1. What can you do to help this patient and her family?
2. What all skills/ knowledge/ contacts you currently have can help
3. From whom else can you seek further help in your region?

### Introduction

The World Health Organisation 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 by means of 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.

### Key points 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 patients 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 that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

### WHO definition of palliative care for children

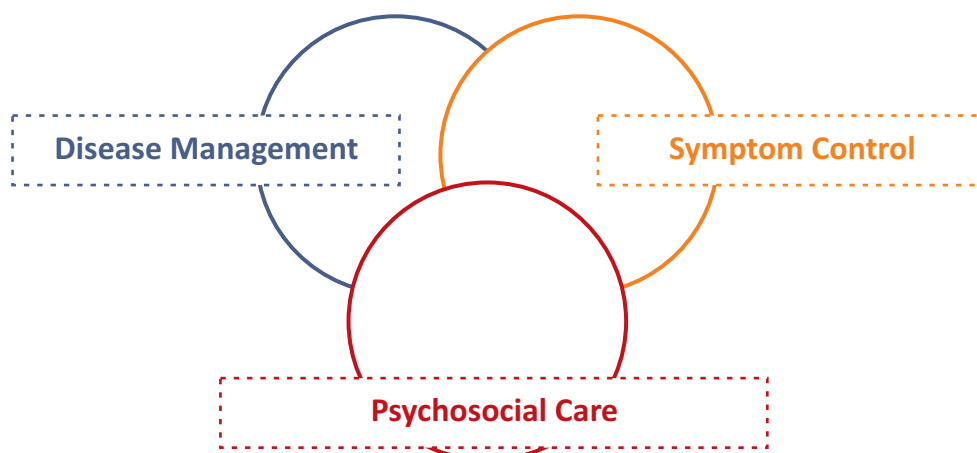
Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows (the principles apply to other paediatric chronic disorders too)

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 multidisciplinary 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, in community health centres and even in children's homes.

### What is different about palliative care?

Usually, health-care professionals tend to focus mainly on physical problems – organs and their diseases. Palliative care recognizes that people are much more than the organs put together; 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 faced by a sick person and his/her family are not just physical; there may be a psychological, social and spiritual concern which are as important as any other problem. Sometimes problems in one area may worsen other existing issues; for example, pain is often worse when people are anxious or depressed. It is only when we address all these aspects we could help the person as a whole. This holistic approach distinguishes Palliative care from conventional medical care.



## What is the history of palliative care?

The word "Palliate" is derived from the Latin word 'pallium' meaning cloak, i.e., all-encompassing care that "cloaks" or protects the patients from the harshness of the distressful symptoms of the disease, especially when cure is not possible. It is person-focused and seeks to address the issues, which are of most concern to the patient at that stage.

Palliative care is not a new speciality. Consideration of the sick has been a constant concern of human society throughout history. We have ancient traditions in India, for exceptional care and attention for those who are very old, ailing or dying. The eighteen institutions built in India by King Asoka (273 – 232 BC) had characteristics very similar to modern hospices. We are presently building on these ancient traditions as well as the expertise and wisdom of pioneers in this field to develop palliative care services.

The modern hospice movement is attributed to Dame Cicely Saunders, who founded the first modern hospice - St Christopher's Hospice in London in 1967. Dame Cicely was triple-qualified professional, having practiced as a nurse, social worker and doctor. This background influenced the way she approached her patient's concerns. This has led to the development of modern palliative care with its holistic dimensions.

## Who needs Palliative Care?

- Cancer
- HIV/AIDS
- Dementia
- Progressive neurological disorders: Parkinson's disease, Multiple sclerosis, Motor neuron disease, Stroke
- Progressive systemic diseases: COPD, ILD
- Heart diseases
- Liver and kidney dysfunctions due to various causes
- Old age and other degenerative disorders

As a Community Health Officer, you are likely to meet people in a variety of settings who may benefit from palliative care and support. Through the chapters, we shall look at the approach, knowledge and skills required in providing good quality palliative care.

## What is the need for Palliative Care in India?

- Less than 4% of India's 1.3 billion people have access to any palliative care
- 1 in 5 suicides in India is committed by a person living with a progressive, chronic or life-limiting condition
- 55 million people in India every year are pushed below the poverty line by catastrophic health expenditure
- While the lower-income groups suffer significantly due to the above reason, paradoxically the affluent

in our country are also marginalised, due to the absence of palliative care in health-care institutions, including both government and private sectors.

- There are millions of people who cannot access a health-care facility because they are bed-bound or are elderly and living alone with no one to accompany them. Care must reach them in their homes.
- Socially and culturally marginalised groups – women, children, the LGBTQI community, people with mental health conditions, migrant populations, prisoners, 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 every year, over 5 million need palliative care, but less than 1% can get it. There are 2.8 million new cancer cases every year. Two-thirds of these are incurable by the time they reach the hospital, and 70 to 80% of them 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. Besides pain, these patients may suffer symptoms like nausea, vomiting, constipation, breathlessness, smelly wounds, lack of sleep and hunger, tiredness and weight loss, worry about the change in the body and looks, sexual problems, social and mental isolation loneliness, worry, anger, sadness, anxiety and depression, helplessness, guilt, financial problems as well as spiritual issues like - "Why has God done this to me, What have I done to deserve this?".

### Definition of terms

- 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: This refers to a philosophy of care of the whole person and all that matters to her/him. It is NOT a specific building or service and may encompass a program of care and array of skills delivered in a wide range of settings – hospital, home or hospice.
- The holistic approach to care: It is care, upholding all aspects of a person's needs, including psychological, physical, social and spiritual needs.
- Supportive care 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 counseling. It helps the patients and their families through periods of pre-diagnosis, diagnosis, treatment, cure, death and into 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 in a complex way 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 out-

patient care (assessment, evaluation, management), patient family education, linking with community-based care facilities (GPs, home-based care programs, link centers) and also acute episodic needs and care during advanced stages of the disease (in-patient services).

- **Caregivers:** Refers to the relative or friend, who takes care of the patient. It may also refer to the paramedical professional who is involved in the program.
- **Multi-disciplinary care:** Multi-disciplinary care occurs when professionals from a range of disciplines with different and complementary skills, knowledge and experience work together to deliver the most appropriate health-care. Here, physiotherapist, social worker, psychologist, nutritionist etc. have significant roles to play along with doctors & Community Health Officer. This approach aims at the best possible outcome based on the physical and psycho-social needs of a patient and family. As the needs of the patients change with time, the composition of the team may also change to meet these needs.

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

- **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 its relevance may be a path chosen by some. A person may be spiritual without being religious. Spiritual pain is when these dimensions get disturbed or questioned, leading to suffering. E.g. I did not drink, smoke, was kind and fair throughout my life. 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 be allowed to have peaceful, natural and comfortable death, rather than being subjected to aggressive, isolating, distressful, costly and invasive interventions. An example for an undignified death would be a patient with multisystem failure being kept "alive" with long term mechanical ventilation and regular dialysis in an ICU setting.
- **Bereavement support:** When a person dies, we say that their family is bereaved. This means they have lost someone precious and close to them and are grieving. The support given to the family to go through this period and get back to a regular productive life is called bereavement support.

### **When is Palliative Care Appropriate?**

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 centres with chemotherapy or radiotherapy services, HIV clinics and super-speciality centres [Spine centre] are competent in providing interventions for diseases but not well trained with helping patients with symptom relief, psycho-social problems such as anxiety, grief, isolation and stigma. This often leaves the patient unsupported and may in turn influence compliance to curative inputs itself.



Palliative care, when integrated into such programs, can complete the care inputs and also improve compliance to treatments and hence 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 patient and their family.

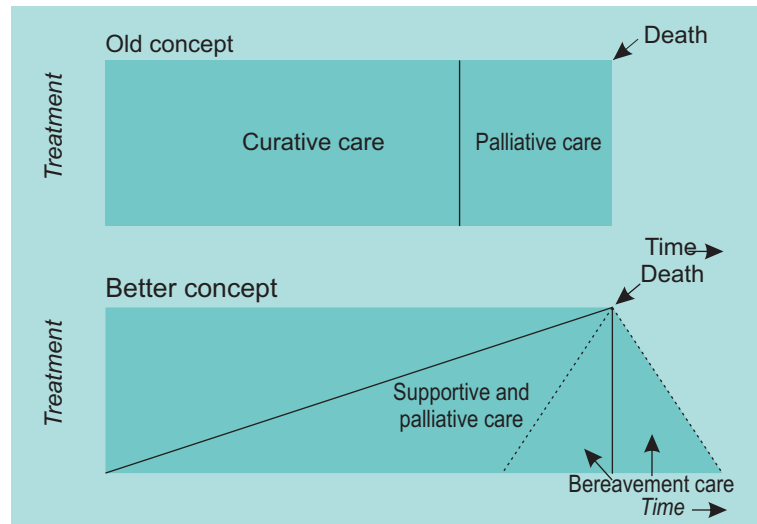


Fig:1 Palliative care model

With the progress of the disease, the needs of the person may change, and palliative needs may overshadow curative treatment.

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.

### At diagnosis

There is an increased need for communications here. E.g. Clarifications on the diagnosis of cancer, the impact of that particular cancer, available interventions and adverse effects of interventions, expectations of cure, are all to be discussed with the patient for decision making. It is essential to communicate effectively with patient and family, provide symptom control and maximise support to help complete a curative therapy.

### Post cure phase

This is a phase with heightened anxiety, where the patient needs adequate information to clarify doubts and fears and support for their genuine concerns. Few distressing symptoms due to the curative therapy, e.g. lymphedema of 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 inputs to go through the matrix of complex phase.



## Terminal phase

Here the emphasis would be to allow a dignified peaceful and symptom-free dying without undue burden on 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 comprehensive cancer care

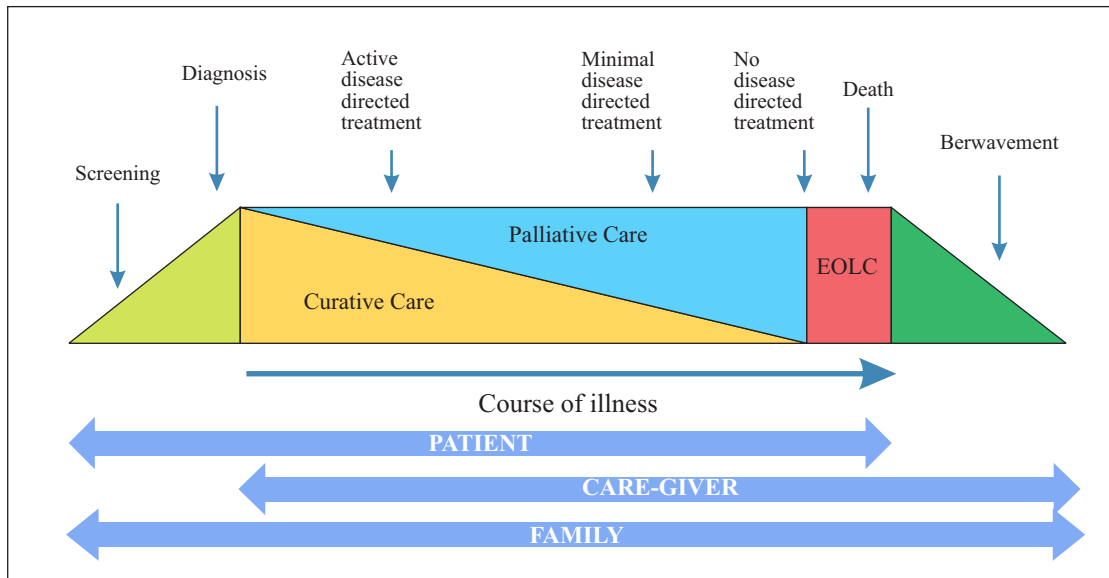


Fig 2 Different aspects of palliative care during each stage

## Where can Palliative Care be given?

The disease brings in its wake, innumerable physical and psychological difficulties for the patients, which multiply many times over if the condition is incurable and life shortening. The problems that would ensue when a family member suffers from the terminal disease are especially dire in a society where most people barely manage to make ends meet.

## Let us examine the problems ordinarily faced by patients in our society:

- Physical afflictions from the disease symptoms such as pain, incurable sores, breathlessness and other ailments.
- Anxiety about the disease and eventual death.
- The financial debt that a family could potentially face resulting from expenses incurred during the care and treatment of the patient.
- The inability for the patient and family members to continue their professional life leading to further financial
- Hardship and other social problems.
- Bitter memories of frequent humiliating experiences at hospitals and elsewhere.
- Ignorance or nagging doubts about available treatment regimes.

- h) Difficulties in accessing places where proper treatment is available.
- i) Spiritual problems related to life and death.
- j) Apprehensions about the fate of the family after the patient's death.

Palliative care can be given anywhere - at home, in the hospital or a place for the terminally sick, which is called a 'hospice'. In India, homecare is considered better because most of the patients are more comfortable in their own home. It is not only cheaper but also allows the family to take care of their loved one without having to travel or lose out on employment. Social support is also more easily available in their native place. It is not difficult to see that most of the problems are social and beyond the scope of a physician, nurse or the hospital to solve.

Palliative care can be provided at any level of care- small primary health centres, secondary level hospitals or the referral level centres, along with the patient's regular treatment. It should be included in existing health-care at all levels of care. Low-cost effective palliative care can be delivered as part of primary care even in far-flung areas. Most of the palliative care is required in the community. It can be provided by training doctors & Community Health Officer in rural areas along with community health workers, volunteers and family members. Some patients with difficult symptoms may, however, need to be referred for specialist-level palliative care.

#### Myths and facts:

What palliative care is not	What palliative care is
NOT restricted to end of life	Needed from the time of the beginning of illness-related suffering, along with any disease-specific treatment.
NOT only for the end of life.	All along the course of the disease
NOT only for cancer	For any life-limiting illness
NOT the last option – when there is no hope	Provides realistic hope of achievable targets with the treatment of suffering, restoring dignity, and when the time comes, a death as free of suffering as possible.
NOT giving up	Filling life into remaining days, nurturing relationships.
NOT euthanasia	The viable and humane alternative to euthanasia in the vast majority of instances. People demand euthanasia because they find their suffering to be unbearable. Through palliative care, we can significantly reduce the suffering and thereby reduce the number of people seeking to end their lives.

#### What are the Models of palliative care provision?

Palliative care can be given anywhere - at home, in the hospital or a place for the terminally sick, which is called a 'hospice'. In India, homecare is considered better because patients are more comfortable in their own home. It is the most cost-effective and convenient option in India where close-knit relatives preferable stay together

Palliative care can be provided at small primary health centres, secondary level hospitals or the referral

hospitals, along with the patient's regular treatment. It should be a part of existing health-care at all levels of care. Low cost, effective palliative care can be delivered as part of primary care even in far-off areas. Most of the palliative care is required in the community and can be provided in villages by training doctors, nurses, community health workers, volunteers and family members. Some patients with difficult symptoms may need to be referred for specialist palliative care.

**Out-patient Services:** Addresses the needs of ambulatory patients. In many Palliative Care (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 for 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 the patients living at home but brought in daily for clinical and social care. These are community-based service centres run by Non- Government Organizations.

**Home-based palliative care services:** It is based on the concept of caring the patients at home. This is continued need-based care for homebound patients. This facility meets the needs of patients to be at home, amongst their family and friends, during a time in life when they are most vulnerable; and continued through their terminal stage.

**Community-based palliative care services:** Home-based services can become even more effective when the local community takes ownership and an active role in providing services within their locality. This model is being effectively practiced in Kerala through the Neighbourhood Network in Palliative Care [NNPC]. The training of volunteers can positively influence the overall response of the community to the health care needs and related policies.

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

It is now well realized that specialist palliative care services alone will not be able to address the needs of an enormous number of patients requiring palliative care. Availability of simple, effective protocols for symptom relief and a low technology approach, in the background of the inability of hospitals, to offer 'Total Care' for the rest of the life of a patient with advanced diseases, make palliative care a much needed component of Primary Health Care. As early as 1990, World Health Organization had recommended that "Pain relief and palliative care programme should be incorporated into the existing health-care systems: separate systems of care are neither necessary nor desirable" and "to ensure that equitable support is provided for a programme of palliative care at home" and that "most patients' palliative care needs do not require specialist palliative care.

Primary health care teams have a significant advantage in the fact that they know the patients in the region over long periods of time. They can also identify patients from their cancer and chronic disease registers who might benefit from an early palliative care approach. Public health experiments integrating palliative care into primary health care systems have shown that cost-effective good quality care is possible at the community level even in a low-income country.

## Chapter 2:

# Home Care

### Learning Objective

**At the end of the session, you should be able to**

- 1) Describe the advantages of home care
- 2) Describe types of home care
- 3) Describe CHO's role in-home care

Ravi, a 35-year-old painter, had a fall from a height, causing permanent damage to the spinal cord. He is now at home after getting discharged from the hospital. Both of his legs are paralyzed. He is on a catheter to pass urine. He has two children, aged 8 and 4. His wife is also neither equipped nor trained to earn money.

**Discuss how home care team can help him with:**

- o Mobility
- o Activities of daily living
- o Personal relationships
- o Anticipated risks
- o Rehabilitation

### Introduction

Every patient has the fundamental right to receive a good quality of care at the place where he/she lives. A home is a place of memories, familiarity and safety, a place where we remain comfortable, relaxed and confident and the best place for freedom of choice and autonomy. It is possible to manage patients with advanced diseases at home. Establishment of affordable, accessible and quality palliative care facilities in the community will reduce the hospitalization of patients with incurable illnesses. This will be a welcome step as people will be at home during the end-stage of their lives. Establishment of quality community-based health-care services at a home level will provide emotional and spiritual support, and helps in preventing and minimising complications in bed-ridden patients. This can be done in partnership with the family/ neighbourhood/ local community as they have a keen interest in the wellbeing of the patient.

End of life Palliative Care patients are mostly bed ridden and cannot come to an OPD of a hospital. Such patients will need to be cared for at a hospice or their homes. Since most of our patients prefer to be cared at homes, home care palliative care services should be provided.

Home based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence.

It is also cost effective and as it does not entail travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments.

### Some additional advantages of home care include:

1. Easy access to care: The patient and family have access to advice and to all aspects of palliative care (physical, psychological, social and spiritual) at their doorstep.
2. More effective caring: Advice, training and additional support for the family is available so that they can become more effective in their role as care givers and feel abler to manage and cope.
3. Access to complementary services: The home care team can facilitate liaison with complementary and supportive services when required. The patient and family do not have to go out seeking such support on their own.
4. Expert referrals for the patient: The team can facilitate referral to other medical and nursing specialists involved in palliative care thereby ensuring the best possible care for the patient.
5. Maintains confidentiality: This is especially important for people with Cancer & HIV/AIDS who may otherwise be shunned by the community out of ignorance and due to misconceptions about the disease.
6. Spreading awareness in the community: Wherever appropriate, home care programmes can be used to spread awareness about palliative care. It is often the case that when a family is nursing someone with cancer their friends and associates become more aware and are more willing to discuss issues around terminal care. The family being cared for, too, can become ambassadors for the cause.
7. Mobilizing local resources: Local support groups and volunteers can be mobilized to support patients and care givers living in their particular area. They would be more willing to do this not only because they may know or have personal ties with the people affected but because it is much easier for neighbours to help each other than travel long distances to do so.
8. Training opportunities: Training in palliative care can be offered to medics, paramedics, community volunteers and care givers in the area being covered by the home care team.
  - Home care thus provide an avenue where palliative care can be practiced in all its domains [Physical, Social, Psychological, Spiritual] most effectively. The aim is to address “Total Pain” of patients and their Care Givers and improve the quality of life of the patients and their relatives.

### Composition of a Home Care Team:

- The Home Care Team consists of professionals trained in Palliative Care namely a Medical Officer, a Community Health Officer, a Nurse, Multipurpose Health Worker & community volunteer. All the member of the team need not be available for all the visits. The composition of team can be decided based on the type of patients during the visit. The visit would be arranged and co-ordinated by ASHA worker.

### How Does a Home Care Function?

- Each team caters for an area served by the Health and Wellness Centre or Primary Health Centre.
- ASHA will identify bed-ridden patients and others needing palliative care be offered home care visit. This is followed by visits by ANM/CHO for further assessment using Palliative care screening tool (Annexure-1).
- The first visit to the patient’s home takes 2 Hours. The Palliative Care issues of the patient and the

family are identified (Medical, Nursing and counseling). Urgent issues are addressed during the first visit.

- The patients are categorized into High, Middle and low priorities depending on their Palliative Care needs. The High priority patients are visited once/ twice or more often every week. Middle priority patients are visited once a fortnight. Low priority patients are visited once a month. These priorities are changed as and when required.

**Home-based palliative care is considered the backbone of palliative care services.**

**The following are the reasons for providing home-based palliative care.**

1. Patients are cared for in their milieu and home environment. They are much more comfortable than in a hospital, which is alien to them and is usually associated with fear and anxiety.
2. The expenses incurred by the patient and his/her family are significantly less when home-based palliative care is provided to them than when they receive care from a hospital-based care setting.
3. The difficulties experienced by the patient and his/ her family during transportation to hospitals are completely avoided when care is provided at patients' own home.
4. Visit by a care provider to the patient's home provides an opportunity to assess a complete picture of the patient and the family, which is crucial to plan the care.
5. There is only minimal disturbance/disruption to family dynamics when the patient is cared for at home than in the hospital.
6. There is a possible financial gain to the family as expenditure in terms of transportation charges, and in-patient charges are avoided when the patient is cared for at home.
7. The involvement of the family in patient care is better when the care is provided at home.
8. Networking of neighbours and their involvement in patient care can be effectively achieved through home-based palliative care.
9. The quality of death and dying experience is very often better when a patient receives home-based palliative care.
10. Home-based palliative care is less expensive and less demanding on health-care infrastructure than a hospital-based care setting.
11. Several individuals do not prefer to go to a hospital and receive treatment. For such individuals, home-based care is an ideal model to access care.

**What are the advantages of home care?**

Home-based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence. It is also cost-effective and as it does not entail travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments. Some additional advantages of home care include:



1. **Easy access to care:** The patient and family have access to advising and to all aspects of palliative care (physical, psychological, social and spiritual) at their doorstep.
2. **More effective caring:** Advice, training and additional support for the family are available so that they can become more effective in their role as caregivers and feel abler to manage and cope.
3. **Access to complimentary services:** The home care team can facilitate liaison with complementary and supportive services when required. The patient and family do not have to go out seeking such support on their own.
4. **Expert referrals for the patient:** The team can facilitate referral to other medical and nursing specialists involved in palliative care, thereby ensuring the best possible care for the patient.
5. **Maintains confidentiality:** This is especially important for people with Cancer & HIV/AIDS who may otherwise be shunned by the community out of ignorance and due to misconceptions about the disease.
6. **Spread awareness in the community:** Wherever appropriate, home care programmes can be used to spread awareness about palliative care. It is often the case that when a family is nursing someone with cancer, their friends and associates become more aware and are more willing to discuss issues around terminal care. The family being cared for, too, can become ambassadors for the cause.
7. **Mobilising local resources:** Local support groups and volunteers can be mobilized to support patients and carers living in their particular area. They would be more willing to do this not only because they may know or have personal ties with the people affected but because it is much easier for neighbours to help each other than travel long distances to do so.
8. **Training opportunities:** Training in palliative care can be offered to medics, paramedics, community volunteers and carers in the area being covered by the home care team.

### **Who needs home care?**

- Chronically ill patients
- Patients with difficulty in coming to the hospital due to physical disability
- Patients who are poor and have financial constraints
- Patients who lack conveyance facilities or are too sick to travel to the clinic
- Patients who lack caregivers
- Patients who feel hospital stay upsets the normal rhythm of life since it involves high expenditure for accommodation, food, travel and at times, disruption of children's education
- Patients who feel that treatment by proxy/relatives can be difficult
- Patients who are terminally ill and bed-ridden who cannot be brought to the hospital
- Mental disorders if trained personnel are available
- Children with developmental disorders if the team can get help from trained personnel

The following are examples of diseases that require home-based palliative care. Alzheimer's and other



dementias, cancer, cardiovascular diseases (excluding sudden deaths), cirrhosis of the liver, chronic obstructive pulmonary diseases, diabetes, HIV/AIDS, chronic kidney diseases, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, drug-resistant tuberculosis (TB), advanced age, spinal cord injuries, mental retardation, congenital anomalies and patients whose mobility is limited due to various reasons.

### **Who can give home care request?**

#### **Home care request from the following persons can be accepted**

1. The patient
2. Family caregivers
3. Neighbour/Friend
4. Community caregivers
5. Field staff
6. Hospitals
7. Health care professionals
8. Other palliative care centres
9. Governmental/non-governmental organization

When home care request is accepted from a non-family member, the home care team should call the patient/family and confirm the registration.

### **What are the types of home care?**

1. Doctors Home Care (DHC): Doctor, Nurse, Volunteer
2. Nurses Home Care (NHC): Nurse, Volunteer, Trainee
3. Volunteers Home Care (VHC): Volunteer
4. Physical Medicine Rehabilitation Home Care: Physiotherapist, Nurse, Physiatrist
5. Psycho Home Care: Social Worker, Volunteer

### **What We Do in Homecare**

- a) Evaluation and treatment of physical symptoms
- b) Adjust medication as needed
- c) Offer psycho-social and spiritual support
- d) Take time to be present at the homecare site
- e) Empower and teach the patient about self-care by using resources available at home
- f) Empower and educate family to care for the patient
- g) Assess social problems
- h) Care of relatives

### **Who are the patients who should receive higher priority for regular homecare visits?**

- Accessibility: Homecare priority is given to patients with limited accessibility. The limited accessibility could be due to physical constraints, financial constraints and geographic constraints.
- Unsettled problems: Patients with poor symptom control and end of life symptoms will require frequent homecare visits.
- Patients who require procedures (like catheter change)

### **What are the common nursing procedures**

- Administer parenteral drugs such as IV fluids
- Naso-gastric tubes
- Catheterisation
- Wound care
- Mouth care
- Bowel care with suppositories, enema and manual evacuation
- Ascites tapping
- Lymphodema assessment and massage
- Colostomy care

### **What are the benefits of Home Care?**

- Patient and family feel support in a familiar environment
- Patients receive individual attention
- Less social isolation
- Helps to mobilise local support
- Full assessment of patient, family and environment
- Patient remains part of the family
- Creates an understanding of family dynamics
- Prepare patient and family for any anticipated difficulties including the death of their loved one
- When there is lack of carers, the home care team can mobilise local support from friends and neighbours
- Patient may feel more in control at home with less anxiety and better management of disease symptoms

### **What are the common skills required for a CHO?**

#### **To be effective in homecare, CHO should have the following skills:**

##### **1. Communication skills**

- Active Listening – This is different from hearing. It is essential to understand what is said by patients, families, colleagues. If not able to understand, ask and clarify. Do not assume things.

- You should be able to speak clearly and avoid medical jargons so that information is effectively conveyed
- You should be able to read and write clearly

## **2. Recognise who needs help**

- You should be able to identify persons who can benefit from palliative care. A screening tool is annexed, which can be used for initial survey/screening
- You should be able to find out the physical, social, emotional issues of the patients and family. A format for the initial detailed assessment is annexed
- These issues may need discussion with team members before finalising the management plan

## **3. Provide assessment and guidance**

- You should have good judgment and be able to decide the actions that can be carried out at their level
- You should help the patient and family take suitable decisions and help them carry these out
- All the information about the patient and family is strictly confidential, to be discussed only with necessary team members so that the patient's privacy and dignity are maintained.

## **4. Facilitate referrals/networking:**

- You should know when to refer a patient and also the resources/ facilities available in the community/ region, which can be helpful.

## **5. Working with the community**

- You should be well connected to the community and understand the behaviour and reaction of people
- You should be sensitive to the cultural issues
- You should not let their own political, religious or cultural beliefs and views influence their work
- You should not take advantage of the helplessness of the patients and families to push their agenda

## **6. Capacity building**

- You must try to improve their knowledge and skill. This helps improve patient care and reduce work-related stress.
- You should be able to teach patients and families on subjects related to health

## 7. Other desirable skills are:

- Leadership skills: You should have credibility within the community, be a role model to others and be able to mobilise resources and people from the community.
- Management skills:
  - You should be able to organise the National programme activities at your level. E.g. planning events and time tables, getting supplies and preparing reports. – You should know how to document the problems and reports.
  - You should act as advocates for palliative care and their patients and should raise their problems at appropriate forums.
  - You should evaluate the services from time to time and take part in surveys and data collection. The following steps are suggested while visiting people at home:
- Know the patient and family well. Even if you know them, cross-check beforehand the names, the disease and socio-cultural status.
- If on a follow-up visit, check the problems they had, the management planned and anything that the care team had to take care of.
- Address the patient and family respectfully
- Introduce yourself and the team members
- Explain the purpose of the visit
- Try to start a friendly conversation
- If there are forms to fill, it can be done later during the visit.
- Listen actively
- Ask about social, emotional, financial and spiritual problems. You may start from the most distressing issue and move on to the others.
- The patient and family may not share all their feelings during the first visit but may do so later. If they do not want or are uncomfortable discussing a particular topic, do not force them. You can discuss these issues later when a good rapport is built.
- Allow them to ask questions. If you are not very sure about the answers, say so. You may discuss with others before answering.
- Discuss with appropriate persons and experts in the team if needed. Clearly explain the management plan to the patient and the carer.
- Do the necessary and appropriate interventions.

- Document your visit, the information gathered, and the procedure is done.
- An abridged version of the initial assessment format, which can be used for documenting the follow-up visits is annexed.
- Plan further follow-up if required and date for next visit. Communicate this to the patient and family

## Chapter 3:

# Communication Skills

### Learning Objective

At the end of this session, you should be able to

1. Describe why communication skills are essential
2. Identify the barriers to effective communication
3. Recognize the do's and don'ts in communication
4. Enumerate the steps of effective communication
5. Explain how to accurately convey the needed information and explanations to patients, families, and colleagues
6. Describe how to deal with extremes of emotions (anger and denial) Describe the steps of communicating bad news.
7. Describe how to deal with collusion
8. Formulates a plan of care based on available information and prognosis
9. Demonstrate empathy to patient and family with a terminal illness

### Group activity

Group 1 discusses the following point: “Imagine you as a patient visiting a hospital for consultation. How do you expect the ‘doctor’ to talk to you?” List the desirable characteristics of a good speaker

Group 2 discusses the following point: “You are a patient who came to your doctor with a problem. How do you want your doctor to listen to you?” List the desirable characteristics of a good listener

### Introduction

Communication is the exchange of ideas or feelings between two or more people on a common background or agenda. Communication can be verbal or non-verbal. Process of communication is complex, and more than 70% of communication takes places through non-verbal means.

Good communication is a trainable skill. Proper communication is vital for the wellbeing of the patient and the family and satisfaction from work. Research in health professional-patient communication has consistently shown that there is room for improvement in the way physicians talk with their patients. Studies indicate there is a significant unmet communication need for information about the disease, prognosis and treatment options, intent, side effects and complications.

### Why We Communicate?

- To convey information or ideas
- To deepen our understanding of issues
- To gain acceptance and trust

### **What is the need for communication skills?**

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 to handle the emotional responses to the illness and deal with the uncertainty.

It helps the Community Health Officer to understand the symptoms, their sequences and their impact on the patient's quality of life and bring in clarity on the clinical condition. The Community Health Officer thus gets an understanding about shared and balanced decision to be evolved, based on patient's values, beliefs and priorities yet supported by clinical evidence and rationale from a caring treating team.

### **What if we fail to communicate?**

- It may lead to poor symptom control
- The patient may not comply with 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 of distress
- There can be situations with escalating conflict
- The team that does not communicate effectively may find an enquiring patient as 'too demanding'. This can impact on the therapeutic relationship.
- Medico-legal problems stem primarily from poor communication and the misperceptions and misunderstandings that ensue.

### **Aims of effective communication in a CHO- Patient relationship**

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

### **What are communication skills?**

Acknowledging and understanding the concerns of the patient and family and responding most appropriately to bring in clarity in their current situation.

### **What are the Core Principles of communication?**

- Respect
- Empathy
- Trust
- Unconditional positive regard

### **What are the consequences of poor communication?**

- Poor symptom control
- Depression
- Increased patient distress and anger
- Lack of co-operation and increasing demands from the patient

### **Barriers to effective communication**

#### **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 perception that we are too busy
- Unable to handle the patient’s emotions
- Unable to improve the situation.
- Fear of the untaught
- Fear of being blamed

#### **Patient’s problems in communicating with us**

- They think we are too busy
- They think we are more interested in their physical care
- They believe that we don’t want to know about any emotional problems
- They are frightened to complain in case we stop treating them
- They are frightened of going out of control
- They may be terrified of having the truth revealed

### **What is the problem arising in communication?**

- Distancing behaviours
- Pretending to be busy
- Selective attention to safe physical aspects
- Failing to explore beyond physical issues
- Premature/false reassurance
- Premature normalisation
- Jolly along
- Inappropriately introducing humour
- Concentrating on Physical task
- Using euphemisms to mislead



- Disappearing from the stressful situation
- Patronising and talking down to patients
- Using medical jargon

### Examples of Good and Poor Communication Skills

Principle	Poor communication	Good communication
<b>Ask open questions</b>	Is your pain better today? This is a closed question and restricts and forces the patient's response.	How are you feeling? This is an open question and allows the patient to talk about what is the most important issue for her/him
<b>Be empathetic</b> E.g., Pt: I feel terrified when I am short of breath	Ns: take these tablets, and your breathing will improve	Ns: breathlessness can be very frightening; what sort of fears do you feel when you are breathless?
<b>Balancing hope and truth</b>	Ns: There is nothing more we can do, your disease is incurable, and there is no point in continuing in staying in the hospital. Here the nurse may be destroying hope irrevocably	Ns: I am afraid there is no more treatment available to cure your disease. But we can keep you comfortable with regular evaluation and medications. We are with you.
<b>Respectful confidentiality and avoiding unhealthy curiosity</b>	E.g. Pt: I feel distressed by the fact that this cancer was the direct consequence of the abortion that I had when I was 17 years. I have not disclosed this to anyone.	Ns: Were you not married then?Ns: I think we need to discuss this more as it is a very significant reason for your distress. Be assured that everything that we discuss will be kept confidential.
<b>Therapeutic relationship</b>	Ns: You have not taken medicine for your pain as advised. Don't waste my time. Here, the nurse is not interested in understanding the reasons why the medicines were not taken and correcting them.	Ns: Tell me why were you unable to take the medicines? I would like to understand further. Did you have any trouble when you started them? Do you have any questions or clarifications?

### Basics steps of communication

- Preparing for listening
- Questioning
- Listening effectively (Facilitating) showing that you have heard
- Responding

### Preparing for listening

- Introductions
- The physical context
- Sit down
- Get physical objects out of the way

## Non-verbal communication

- Eye contact
- Posture
- Facial expression
- Pitch and pace of voice
- Touch

## Questioning

- Open questions
- Closed questions
- Leading questions
- Biased questions (disguised statements)

## Effective listening and facilitating: Ten Commandments

- i. Stop Talking
- ii. Put the speaker at ease
- iii. Show him/her that you want to listen, maintain eye contact
- iv. Remove distractions
- v. Empathise with him/her
- vi. Be patient, tolerate short silences
- vii. Hold your temper
- viii. Don't argue or criticise
- ix. Ask questions
- x. Stop talking

## What are the steps for effective communication?

- 1) Build a relationship
- 2) Open the discussion
- 3) Gather information
- 4) Understand the patient's perspective
- 5) Share information
- 6) Reach agreement on problems and plans
- 7) Close discussion sensitively

### 1. Build a relationship:

- o Set the scene. For dealing with a request like Gita's, you need the time and privacy
- o Preferably, you could be sitting down at eye level, not too close to invading private space, but close enough to lean forward and touch the patient if the need arises.

- o Convey empathy with your expression and with a statement like, “I see that you are very much worried.” The important thing is to convey that you care.

## **2. Open the discussion**

- o Acknowledge feelings like pain or loss. In the case of Gita, it would be appropriate to say, “It looks like life is a burden for you right now”. Acknowledgement of suffering makes the patient feel that she is understood.
- o Listen actively. Active listening involves eye contact, appropriate facial expression (empathy), body language (leaning forward) and verbal responses like “Yes, I see...”, “and?”, “hmmm”, oh... etc. It also involves encouraging the patient by repeating her last few words and paraphrasing.
- o Listening not only to what is said but also to what is not said – to the facial expression, the body language of the patient, indicating suffering, avoiding eye contact indicating, she is uncomfortable to continue etc.

## **3. Gather information**

- o Explore and find the patient’s level (What does she know? How much does she want to know?)
- o Use open questions or statements which invite responses like,
  - “What do you think might be the problem?”
  - “What worries you most?”
  - “That must have come as a shock to you”

## **4. Understand the patient’s perspective**

- o What does she feel about it all? What questions does she have?
- o Be prepared for emotions and behaviours (sobbing, anger, silence, despair)
- o It may be necessary to facilitate sharing with words like, “could you tell me your thoughts and how you are feeling?”

## **5. Share information**

- o The patient decides the agenda for further discussion. In other words, what she considers important must be discussed at this stage.
- o If she wants to postpone the discussion about further treatment, that should be allowed within a reasonable time frame
- o The patient has a right to know everything; but not a duty to know. Confirm what the patient wants to know.
- o Use common conversational language
- o Check understanding at every stage

## 6. Reach agreement on problems and plans

- o Summarise the problems brought out by the patient
- o Suggest a course of action
- o Answer any questions the patient has
- o Arrive at a course of action acceptable to the patient, making it clear that this is not an iron-clad contract and that the plans are renegotiable

## 7. Close discussion sensitively

- o Avoid abruptness
- o Review and summarise discussion before finishing
- o Leave the door open to talk again

### What are the benefits of effective listening?

- Enables receiver to absorb ideas and information with minimum distortion
- The receiver can make better decisions when he/she has better information
- He/she saves time by gathering more information within a given period with less need for feedback

### Hearing (showing that you have listened)

- Repetition
- Reiteration (Paraphrasing)
- Reflection
- Summarisation
- Prioritisation

### Responding: Types of responses

- The factual response
- The Aggressive/Hostile reaction (“the counter-attack”)
- Judgmental Response
- The Reassuring Response (‘The Pacifier’)
- The empathic Response
- Silence
- Responses do not have to be the complete answer

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

#### Group activity

Instructions: Participants to discuss in groups of 4-5 persons the following statement for 10 minutes and then report back (5 minutes).

Statement: “We some times have difficulties in communication with patients. It can be due to Individual factors (Patient), Individual factors (Nurses), Individual factors (Carer), Social Factors.”

List the difficulties in communicating with a patient having a life-threatening illness.

## Introduction

Effective communication with patients facing progressive disease, with complex problems and an uncertain future is a challenge, and it needs more skills and practice. Patients with advanced and progressive diseases have issues other than physical, and they require compassionate listening and empathetic responses.

### What is not recommended during clinical communication?

- 1) Do not immediately reply to the patient's words. It is useful to enquire for feelings or real questions behind what the patient words.
  - i. E.g., When a patient asks... "Sister, how long do I have?" the implicit question usually is
  - ii. "Sister...now that I have very little time left, what can I expect, how can you help me?"
- 2) Do not philosophise or moralise.
  - i. e.g. "You should not say such things. God gave you life. Trust in God." They may hurt the patient's feelings of conversation stoppers.
- 3) Avoid comparisons. It is insensitive to say that someone else's grief is more significant, and therefore, the patient has no right to grieve.
  - i. 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 like "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 doesn't provide comfort and it destroys trust. Reassurance is essential to maintain hope 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 patronising or condescending attitude. The patient will open up to you only if you deal with her/him with respect.
- 9) Do not force your beliefs or convictions on the patient.
  - i. e.g. "You must regularly chant for strength to endure this" is imposing your own beliefs in patient.
- 10) Avoid sympathy, which is hard to bear.
  - i. E.g. Oh you poor thing; it is so sad you have to go through this terrible disease'. Instead, convey empathy – an attempt to put ourselves in the patient's shoes and to try to understand what he is going through. E.g. "I can see that you are going through a lot..."
- 11) Avoid inappropriate humour.
  - i. E.g. Oh, so you are waiting for your final Visa?! Ha, ha

- ii. 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, and even if accepted, 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”.

### **Managing Anger**

Anger is a response to feelings of helplessness, distress and fears. It may also be a negative result of ineffective communication between health care professionals and the patient/carer/ family members. Anger is often unleashed on a person who is perceived as close (like a spouse, close friends, close family members) or non - threatening (usually security staff, reception staff, attenders, junior nurses and junior doctors). Anger is the source of medico-legal suits. The plain, empathetic and straightforward approach helps.

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.”

### **How to handle anger?**

- The patient may direct anger at you irrespective of whether you are the source of distress or not.
- Be calm, empathetic and use positive non-verbals 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’.
- Summarise the conversation
- Ask if the patient would like to add something or need any clarification
- Assure your continued support & follow up after a stipulated time

### **Managing 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 appears to be a common defence mechanism in the majority of palliative care patients. It varies in its severity and pervasiveness. It has varying effects on the process of adaptation. In some cases, denial reduces anxiety, whereas in some others, it results in excessive delay in seeking help and poor compliance to treatment.

**Questions, like the following, can help in getting an idea about the nature of denial.**

- What do you think about your illness?
- What is your understanding about 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 possibilities of any psychiatric disorders.
- Check the patient's insight – establish what he/she knows. This should include his/her understanding of the diagnosis, prognosis and current treatment regime.
- Listen to the words used and observe the non-verbals of communication when the patient narrates. This will tell you how much the patient knows or how he feels about the illness.

### **How do we manage denial?**

- Ensure that the patient's denial is not due to lack of information, lack of understanding or lack of 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 denial is used by the patient.
- Assess the benefits and risks of denial to the patient's psychological condition and compliance with treatment.
- If the denial is expressed by minimisation 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.
- Last but not least, emphasise to patients that they will not be abandoned. They will be supported and cared for.

### **Difficult Communication**

#### **Group activity**

Instructions: Participants to discuss in groups of 4-5 persons the following statement for 10 minutes and then report back (5 minutes).



A patient with a lump in her breast was seen by the doctor and advised biopsy. Biopsy report turned out to be cancer of the breast. She has not been told about the diagnosis.

- a) You have been asked to inform and explain the diagnosis to her
- b) How will you break this bad news to the patient?
- c) What all preparations do you need?

## Introduction

### BREAKING BAD NEWS

#### General Points

1. You have information about the patient which the patient doesn't have
2. Patient satisfaction does not depend on the time spent
3. Advocacy is the basis of support
4. All questions may not have answers
5. More important questions may be enquired with junior/non-physician staff

### SIX STEP PROTOCOL

#### Step I. The right way of Starting

- Right physical context
- In-person
- Privacy
- With a relative? Friend?
- Introduction

#### Step II. Know how much the patient knows regarding the impact of illness on his/her future.

- Correct phrasing for probing. What has your physician/nurse told you? What were you told before this visit? What do you think caused your illness?
- Assess how close the patient is to the medical facts.
- Listen to the words or phrases that the patient uses
- Note the emotional tone when the patient communicates (Non-verbal & verbal)

#### Step III. Find out how much the patient desires to know

##### Phrasing:

- Are you someone who usually likes to know details of your illness?
- When I go through the prognosis, do you want to know the details?
- Would you like me to discuss just the treatment details?



**Issues:**

- Giving the game away & denying patients the option of discussion
- Asking patients view at this early stage itself could be distressful for the patient

**Discussion:**

- Question is not whether the patient wants to know or not, but to what extent he/she wants to know
- Physicians and nurses are not the only sources of information
- Not discussing is more upsetting than withholding information
- If the patient does not wish to know, avoid forcing the information.

**Step IV. Sharing Information**

**Proceed based on the information gathered in step II & III Two components**

- Divulging information
- Therapeutic dialogue

**Before divulging information,**

- Make a plan for discussing: Diagnosis, Treatment, Prognosis and Support
- It is not essential to state your plan
- Your agenda may not be the same as patients.
- A mentally competent patient when fully informed can reject or accept your agenda

**Step IV. A: Aligning with the patient's level of knowledge regarding the diagnosis and treatment**

Reinforce the concepts that are medically accurate (This helps boost patients confidence in self and the team)

**Step IV. B: Educating to bring patient's perception of the situation closer to reality**

- Assessing the magnitude of the gap
- Close the gap by changing patients understanding in small steps
- Introductory warning shot
- Talk in plain language- no jargons
- Speak clearly, use diagrams if needed.
- Ensure that the information provided is received
- Provide more clarification if needed
- Make sure both you and patient mean the same thing
- Repeat crucial points
- Check your status regarding the probing: how far have you reached in understanding the patient's knowledge about his/her disease
- Never patronise the patients

- Never speak down to a patient. Always use an adult-to-adult conversation style unless the patient chooses an adult-to-child type as a coping mechanism
- Listen to the patient's ideas and unanswered questions
- Try your best to align your ideas with those of the patient's

### **Step V. Responding to reactions**

Bad news, even when it is delivered in a compassionate way, is still bad news. The recipients respond in different ways to this information. Addressing these emotional reactions in a supportive way is very important.

### **Step VI. Planning and follow-up help to clear confusion and devise a feasible plan for the future.**

- Understand the patient's list of problem areas
- Distinguish between fixable and unfixable problems
- Devise a plan of action & explain the plan to stakeholders
- Prepare for the worst while hoping for the best
- Help identify the individual coping strategy
- Identify other support sources and incorporate them in summary report

**Summarise** and open the door for future contact

## **COLLUSION**

*“Please don't tell.”*

Collusion implies information (about diagnosis, prognosis and medical details about the patient) being held by some and not shared with significant stakeholders. Collusion usually occurs when the family conspires among themselves or with professionals to withhold information or lie to the patient. It is often well-intentioned, acting in what is believed to be the best interests of the patient. Usually, the family members of the patient collude, to protect the patient from emotional harm; which they expect would happen if the bad news is broken to the patient. However, this inevitably creates tension because the patient has the right to information.

The professional team treating the patient and colluding with the family members is a common problem. Besides, withholding of information also occurs between the professional team and the patient.

### **The problem of colluding occurs due to many reasons:**

- Patient's lack of trust in everyone close to him/her including the professional team.
- Unfinished business for the patient or family members
- Blocked grief
- Chronic anger
- Depression and suicidal tendencies
- Disturbed sleep patterns
- Disturbed eating patterns
- Disturbed leisure patterns

- Disturbed conversation patterns

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

### **How to handle situations arising from collusion?**

- Acknowledge with family members that collusion exists.
- Acknowledge the family member's ideas about the best option that the patient has in treating his/her disease.
- Speak reassuringly for instance by using phrases such as “you know your brother much better than I do.”
- Empathise with the difficult position the family member is in. For instance, one could say “It must be challenging for you to maintain the secrecy with the patient” or “I guess you don't normally keep important things from your brother.”
- Empathise again and as many times as you can to gain the family member's trust.
- Empathising and asking a direct 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 the family members. In particular, communication could get stifled, and scary leading to more emotional distress and increased isolation with family members (Patient could stop other relatives and neighbours from visiting often).

The patient could also feel anger when he/she realises everyone knows more than he/she knows. One could use the anger to reason with the patient about the difficulty that the current situation is imposing on his/her caregivers. At times obtaining permission from the family members to evaluate the patient's current state of mind and level of awareness about his/her illness is useful to proceed forward with a good plan. If a professional feels strongly about meeting the patient and his/her family members together, then such an arrangement must be made.

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

### **The family members that collude with the professional team and patient could believe that**

- The patient does not know the diagnosis (could be true)
- The patient will give up and die if he knows the truth
- The patient will not be able to cope with the knowledge
- It is their responsibility to shield the patient

### **Steps to manage collusion**

1. Convey to the relative that you are on their side. Do not start by persuading the relative. The message

should be, “You want the best for your mother (patient). I too want the best for her. Let us talk about it and make plans.”

2. Explore the family’s understanding/insight about the illness and reasoning

- Establish whether they are trying to protect themselves or the patient
- Recognise that they may have valid concerns about the patient’s capabilities and past behaviour patterns
- Do they have a correct understanding of their situation?

3. Reassure and explain

- Reassure that you will not walk in and impose information
- Find out if the family already has felt adverse effects of the patient not knowing the diagnosis. Has he been anxious? Has he been in the "bargaining" phase making unrealistic demands about treatment?
- Explore how much this (withholding information) has affected the communication and interaction within their family
- Explain the consequences of keeping the diagnosis from the patient.
- Mention that you recognise the patient's right to information if requested.
- Offer to facilitate the conversation between the family and patient, if they find it too difficult to handle.
- If they are still unwilling, get conditional permission for finding out what the patient already knows.

4. Share information as and when required

- Explore the patient’s understanding, and assess their desire for further information
- Inform the family about the patient’s desire.
- Share information in digestible chunks.
- Inform family members what has been discussed with the patient.
- Encourage open communication between the family and the patient.
- If the situation demands clarifications or explanations, pitch in.

Occasionally patients collude with professionals to withhold information from their family. This is more difficult as the patient has to permit disclosure of information, but the principles are the same as above – sensitive handling, exploration of reasoning, and explanation about consequences, reassurance and offer of facilitation.

**Points to remember**

In reality, you have to achieve two objectives simultaneously

1. To honour the patients right to know, even if family members do not wish it.
2. To identify and acknowledge the feeling and motivation of the family members even if their wishes cannot be met.

### **Relatives collude with the best of intentions**

It is important to remember that relatives only collude because they love the patient and want to protect him/her from the painful truth. But this protection may cause isolation and a sense of worthlessness, making it worse for patients who have a fair amount of awareness about their disease and its seriousness.

## Chapter 4:

# Psychosocial and Spiritual Support in Palliative Care

### Learning Objective

At the end of the session, you should be able to

- 1) Explain the psychological and spiritual issues related to palliative care and in patients with chronic illnesses
- 2) Recognize the psychosocial and spiritual needs of patients and caregivers
- 3) Develop empathic listening skills, identify and respond to emotional and spiritual distress when it occurs.

### Group activity

During home care you visited the house of Kannan, a 33-year-old manual labourer, had a fall from a height, causing permanent damage to the spinal cord. Both of his legs are paralyzed and is on a catheter to pass urine. He has two children, aged 8 and 4. His wife is also neither equipped nor trained to earn money.

Discuss how his present physical condition is going to affect his life and his family's life. Discuss possible issues related to

- a) Finance
- b) Personal relationships
- c) Social activities
- d) Health and social care: accessibility and quality
- e) Work/capacity to work
- f) Sexuality

### How can you help him?

#### Introduction

As a Community Health Officer, you will be meeting patients and their families with the intention of assessing their needs and referring them on to other sources of support. However, there is a great deal that you can do on your own to assist a patient who may be struggling with psychosocial and spiritual issues because of a debilitating and life-limiting illness.

The key to psychological assessment is finding out what the patient wants to know. It is critical to approach the patient with care and patience to understand how the patient feels about their disease. An unrushed and gentle manner will work better in shedding light on their needs and level of distress. How the patient interprets their disease, and its symptoms may be a cause of suffering in itself. However, in-depth probing at the first visit may be inappropriate, as patient's priorities may be different. Some patients may want to know everything, and studies suggest that they are by far the majority, but some would prefer not to have things spelt out at all.

### **Psychosocial issues of people with a progressive incurable illness**

Any physical illness psychologically affects the patient and family. In short-term diseases, the realization and hope that it will be cured, and the support from family and society, help them overcome the temporary difficulties. The situation is different for long term-diseases as those have no cure and get worse over time. Problems related to the sickness, anxiety about the future, financial worry, fear about the family's future, and isolation together create a serious psychological condition troubling to the patient.

#### **These patients have several concerns related to their sickness.**

- 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?)
- Grief/Despair (This will only get worse and end in suffering and death)
- Hope (I shall remain pain-free and continue to function independently).

#### **Fears and anxiety**

Coping with a serious medical illness can be very challenging as a person confronts pain, disability, dependence, the concerns of loved ones and one's fears and anxieties. Nothing prepares a person for such a situation. Dreams are broken, plans left undone, and several unfulfilled wishes remain. Severe anxiety impacts on every aspect of personhood- Physical, Psychological, social and spiritual.

Manifestations of Anxiety are varied and include insomnia, nightmares, dizziness, tremor, apprehension, jitteriness, poor concentration, headache, sweating, palpitations, chest tightness, breathlessness, dry mouth, dysphagia, anorexia, nausea and vomiting, urinary frequency, muscle tension, fatigue, weakness etc. Some anxieties may arise from medical complications of illness or treatment such as delirium, hypoxia, sepsis, poorly controlled pain, adverse drug reactions and withdrawal states.

#### **Some common causes of Fear and Anxiety.**

- Feeling of uncertainty- of diagnosis, treatment, prognosis and time of death.
- Isolation and separation following death.
- Claustrophobia- patients may feel claustrophobic of being confined and buried in a coffin
- Abandonment–by caregivers or health care team
- Pain/suffering -Anxiety and fear that the pain would worsen and suffering might increase.
- Knowledge of advanced/ progressive disease
- Death...more so, it is the fear of the process of dying and fear of the unknown
- Family- future of the family
- Of treatment- e.g. pain during procedure etc., the outcome of treatment and side effects
- Leaving unfinished business-e.g. children to be educated or married, property and financial matters to be settled, reconciliation, pardon and forgiveness.

#### **What can be done?**

Very often, a supportive conversation and a compassionate presence are helpful. The patient needs to realize that

that he/she is still wanted in this world, still deserves love and respect and under no circumstance will he/she ever be abandoned. A compassionate presence does not mean just words. Body language, touch, and proximity everything has a role. Take care not to create any misunderstanding or lose confidence in the family members.

The community health officers is there to listen to the patient, try and understand him/her and not to voice our opinions and force them upon him/her.

- a) Listen attentively. Be a good listener.
- b) Do not consider the patient's problems as insignificant.
- c) Do not force your opinions/beliefs upon the patient.
- d) Do not ignore the patient's queries.
- e) Try to address the social issues that can be addressed.
- f) Do not give any false hopes.
- g) Ensure confidentiality.
- h) Do not force the patient to talk.

## Psychological Distress

Some psychological distress will occur with any life-limiting illness. The ability to recognize and relieve this is an essential skill in palliative care.

### Factors predisposing to psychological distress

- The disease
  - rapidly progressive, clinical features changing frequently
  - present and anticipated disabilities, disfigurement, dependency
  - physical dependence o protracted illness with physical and mental exhaustion
- The patient to not fully understanding the disease, treatment or what lies ahead
  - made worse when no simple explanations are given
  - fear of pain, dying, disfigurement
  - loss (or fear of loss) of control, independence, dignity
  - helplessness, hopelessness, dependency
  - insight regarding (or fear of) poor prognosis
  - anxious personality, pre-existing personality traits
  - pain and doubts whether suffering can be relieved
  - lack of confidence in medical and nursing attendants
  - unrelieved pain
- Symptoms of uncontrolled or poorly controlled symptoms
  - perceived lack of interest in medical attendants
  - unaware of the cause of different symptoms



- treatment
- diagnostic delays, multiple failed treatments
- side effects of therapy
- Treatment team
  - poor communication
  - lack of continuity of care
  - exclusion of family, carers
- Social
  - 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
  - financial hardship
  - fears for family
- Cultural
  - cultural differences in attitude to sickness, suffering, loss, and death
  - language barriers
- Spiritual
  - religious issues
  - spiritual issues, e.g. remorse, guilt, unfulfilled expectations, meaninglessness, sense of life and suffering have no meaning

### **What can be done?**

Better pain control and symptom control methods need to be tried out. Pain can be the root cause of most psychological issues. Also, untreated depression or anxiety may worsen the pain. Good pain management with available opioids may help in improving their coping skills, along with other symptom management.

### **Psychological intervention and effective counselling by way of exploring and acknowledging concerns.**

#### **Early detection and treatment of psychiatric morbidity can influence**

- good psychological outcome
- mood / affective state
- coping style
- treatment compliance
- quality of life

### **Treatment**

- Counselling and education
- psychotherapy
- psychotropic medications

### **Nursing Care**

- Support for the family is also essential.
- How can we help the patient / family come to terms?
- communicating well
- maintaining hope in a realistic way
- setting realistic goals
- scheduling activities
- helping family members
- communicating and interacting with the patient
- creating an atmosphere in which the threat of dying and death may be freely expressed

### **Some preventive measures could be**

- Counselling and education from the time of diagnosis.
- Supportive care through the diagnosis, treatment, failure of treatment, recurrence of the disease, progression of the disease and the terminal stage could help the patient and family glide through smoothly from the curative treatment to palliative care. Thereby acceptance by family members and patients can be well established.

### **Denial**

Denial in a palliative or acute setting is a complex process, which may involve an unsteady process in coming to terms with a frightening prognosis. Denial is the most frequently seen coping mechanism. Denial may result in the patient behaving differently with different people—with close relatives they may appear to know nothing of the illness or its seriousness, but can discuss it openly with another relative or a professional carer.

### **What can be done?**

- treat underlying causative factors before rushing to prescribe anxiolytics or antidepressants    general measures
- a caring, considerate, unhurried, non-judgemental approach
- good listening, good communication
- reassurance about continuing care
- respect for the person and individuality
- allow discussion of fears regarding future suffering, life expectancy even patients ‘in denial’ appreciate such discussions

### **Delirium**

Definition: 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.

### Causes:

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

### What can be done?

- Monitor and record consciousness level, temperature, pain scores, equipment pressure sores, findings of the neurological and rectal examination.
- Administer drugs as per the prescription
- Stop any offending treatment
- Correct metabolic abnormalities
- quiet room, low lights, calendar, clock
- Family support
- Treat reversible causes (dehydration, hypercalcaemia etc.) if consistent with goals of care.

### Spiritual Issues

Spirituality is defined as “a dynamic and intrinsic aspect of humanity through which persons seeks ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature and the significant or sacred. 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.

When people get sicker 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. We are there to walk with them on that journey, not to tell them what to think, feel or believe. It is therefore essential that we don’t try and take the suffering away by trying to impose our spiritual solutions onto their spiritual struggles.

### What can be done?

- 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, or other sources of strength?”
- “Do your illness and grief interfere with expressing your spiritual beliefs?”
- Assess whether patients need help with unfinished business.
- Provide understanding and acceptance. Support crying by offering a caring touch.
- Encourage verbalization of feelings of anger or loneliness.
- When requested by the patient, arrange for priest, rituals, music, prayers, scriptures or images.

- If requested, sit with the patient who wishes to pray, and arrange for a priest at the time of death as requested by the patient.
- Do not provide intellectual solutions for spiritual problems.

### **Sexuality**

Very often, in many cultures, nurses find it difficult/embarrassing to explore sexual issues. Sexual issues can arise from various psychological and physical problems; some of which are:

- A misunderstanding that the disease would spread
- Physical deformity caused by the disease that changes one's attitude about one's own body
- Deformities caused in sexual organs or other sexually essential parts of the body
- Disease or treatment may bring about hormonal changes in the body, thereby causing changes in the ability and interest in sexual life.
- The frailty of the body
- Lack of privacy
- Colostomy, tracheostomy and so on

### **What can be done?**

- Make sure that the patient gets the time and privacy to spend time with the partner
- Encourage the patient to open up on his/her problems and needs
- In the case of patients with diseases that are transmitted sexually (AIDS/hepatitis) allow them to discuss with the doctor about safe methods of sexual intercourse

### **Summary**

The focus of palliative care is the whole person, including biopsychosocial, cultural, and spiritual dimensions of patient needs. Patients with an advanced illness often experience psycho-socio-spiritual distress and symptoms. They are common in palliative medicine and present in patients as well as in caregiver and it need rapid assessment and specific management

## Chapter 5:

# Assessment of Pain

**At the end of the session, you should be able to**

- 1) Demonstrate the concept of “total pain.”
- 2) Develop a comprehensive analysis of patients with pain and identifies the physical, psychosocial, and spiritual components of distress
- 3) Apply and use different tools available for assessing the pain

### Group- activity

Mr Raju is a 60-year-old man with buccal mucosa cancer who is experiencing severe pain in his face from a large tumour, which he rates as a 10/10 on a visual analogue scale. The pain is preventing him from sleeping, eating, and he has no joy in his life. He lives in his home with his wife and two children. Before his illness, he was a bus driver, an occupation that he enjoyed. He currently sleeps outside of his house, so he does not interrupt the rest of his family. When you approach him for the first time, he puts his hand over his face and cries, “please help me.” What would it be like to have such disfigurement and have no relief of the severe pain?

### Questions:

1. What would be the leading cause of his suffering?
2. What interventions would help Mr Raju feel less isolated?
3. What are the most likely causes to have Mr Raju say “Please help me?”

### Introduction

#### What is Pain?

**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).

Pain which is of sudden or slow onset of any intensity from mild to severe, constant or recurring without an anticipated or predictable end and lasting for more than six months, is described as chronic pain.

Chronic pain may be classified as chronic malignant pain and chronic non-malignant pain. In the former, the pain is associated with a specific cause such as cancer. With chronic non-malignant pain, the original tissue injury present but not progressive or has been healed. Identifying an organic cause for this type of chronic pain is more difficult.

Chronic pain differs, from acute pain in that it is harder for the patient to provide specific information about the location and the intensity of the pain. Over time it becomes more difficult for the patient to differentiate the exact location of the pain and identify the intensity of the pain. The patient with chronic pain often does not present with behaviours and physiological changes associated with acute pain.

## Principles of Pain Management

- 1) Remember to consider the 'whole patient'. Symptoms are never purely physical or purely psychological, and all symptoms and treatments will have an impact on the patient, their family and friends.
- 2) Evaluate symptoms thoroughly. Consider potential causes and remember to consider reasons other than cancer. Consider the impact of the symptom on the patient's quality of life.
- 3) Effective communication is essential. Explain in simple terms and avoid medical jargon. Discuss treatment options with patients and their families, and involve them in the management plan.
- 4) Correct the correctable, as long as the treatment is practical and not overly burdensome. Remember non-drug treatments, e.g. palliative radiotherapy for metastatic bone pain.
- 5) When using drug treatments for persistent symptoms, give regularly and also 'as needed'. Keep drug treatment as simple as possible.
- 6) Review regularly and adjust treatment.
- 7) Remember to consider nonpharmacological strategies to help relieve symptoms, e.g. simple repositioning, or the use of a TENS machine may help the pain; complementary therapies may help psychological distress. Although the evidence base for such treatments is not robust, some patients find them helpful.
- 8) Plan in advance. Good communication is essential in establishing patients' wishes for their future care and treatment.
- 9) Keep other staff informed.
- 10) Ask for help.

## Causes of Pain

Many patients do not take the medicines properly, due to lack of knowledge or misunderstanding about the pain killers (at times, ignorance of the family members also becomes a cause for not getting medicines).

<p>Causes of Pain</p> <p>Due to cancer</p> <p>At the spot where the disease first started</p> <p>At the spot where the disease had spread</p> <p>Radiation, chemotherapy, surgery.</p> <p>Cancer-related conditions</p> <p>Constipation, bedsores, emaciation</p>	<p>Things to be remembered!</p> <p>Factors that enhance pain</p> <p>Exhaustion, loss of sleep</p> <p>Anxiety, Despair, Despondency</p> <p>Anger</p> <p>Feeling of isolation</p> <p>Loneliness, Fear</p>
<p><u>Unrelated to Cancer</u></p> <p>Disc prolapse</p> <p>Fracture</p> <p>Burns</p> <p>Stress</p> <p>Gastritis</p>	<p><u>Factors contributing to relief</u></p> <p>Adequate sleep and rest</p> <p>Relief from other ailments</p> <p>Hope - The feeling that there are people to help.</p> <p>The opportunity to open up one's mind</p>

## PQRST of pain

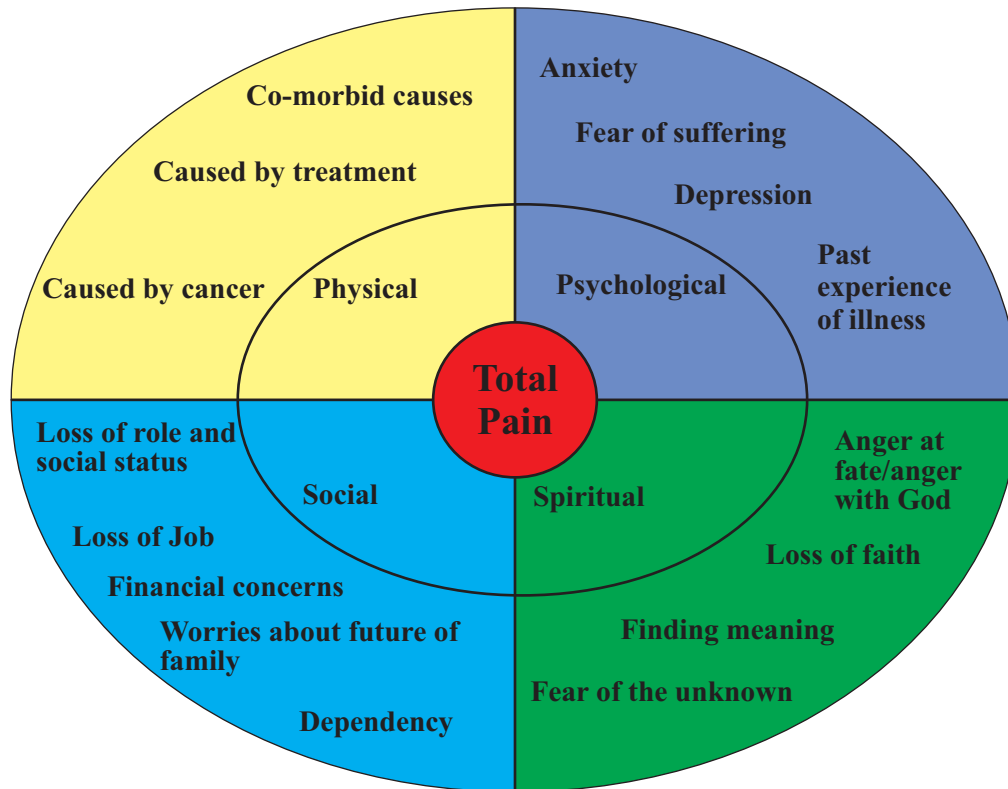
A good understanding of the patient's pain forms the keystone of the development of a treatment plan. If not well controlled, pain can interfere with every aspect of the patient's day, from their ability to carry out simple activities of daily living, such as washing and dressing, to their tolerance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

<p><b>P = Provokes/Precipitating/Palliating</b></p> <ul style="list-style-type: none"> <li>• What causes pain?</li> <li>• What makes it better?</li> <li>• What makes it Worse? What previous treatment have you tried to relieve your pain?</li> <li>• Were they effective?</li> </ul> <p><b>Q = Quality</b></p> <ul style="list-style-type: none"> <li>• What does your pain feel like?</li> <li>• What words would you use to describe your pain?</li> <li>• Is it sharp?</li> <li>• Dull?</li> <li>• Stabbing?</li> <li>• Burning?</li> <li>• Crushing?</li> </ul> <p>( Try to let patient describe the pain, sometimes they say what they think you would like to hear. )</p>	<p><b>R = Radiates</b></p> <ul style="list-style-type: none"> <li>• Where does the pain radiate?</li> <li>• Is it in one place?</li> <li>• Does it go anywhere else?</li> <li>• Did it start elsewhere and now localised to one spot?</li> </ul> <p><b>S = Severity</b></p> <ul style="list-style-type: none"> <li>• 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?</li> <li>• How much does it hurt at its worst?</li> <li>• How much does it hurt at its best?</li> </ul> <p>( This is a difficult one as the rating will differ from patient to patient. )</p> <p><b>T = Time</b></p> <ul style="list-style-type: none"> <li>• When did your pain start?</li> <li>• How often does it occur?</li> <li>• Has its intensity changed?</li> <li>• How long does it last?</li> </ul>
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## Total Pain

The term "Total Pain" coined by Dame Cicely Saunders is used when psychosocial, physical, and spiritual distress, combine to affect the patient. All the components should be addressed and treated to get complete relief from 'pain'. Relief from total pain improves the quality of life of the diseased and the family. Pain is traditionally perceived as "TOTAL PAIN" with Physical, Social, Psychological and Spiritual dimensions. Exploring a patient's anxiety and frequent misconceptions related to these factors can be very beneficial inappropriate management of pain.

The pain will not be adequately controlled unless patients feel a degree of control over their situation. To ignore such psychological aspects of care may often be the reason for persisting pain. Having prescribed analgesics, the patient's pain should be constantly evaluated, and the response to treatment reviewed regularly. Thus, a holistic approach to treatment is essential in palliative care.



### Assessment and Documentation of Pain

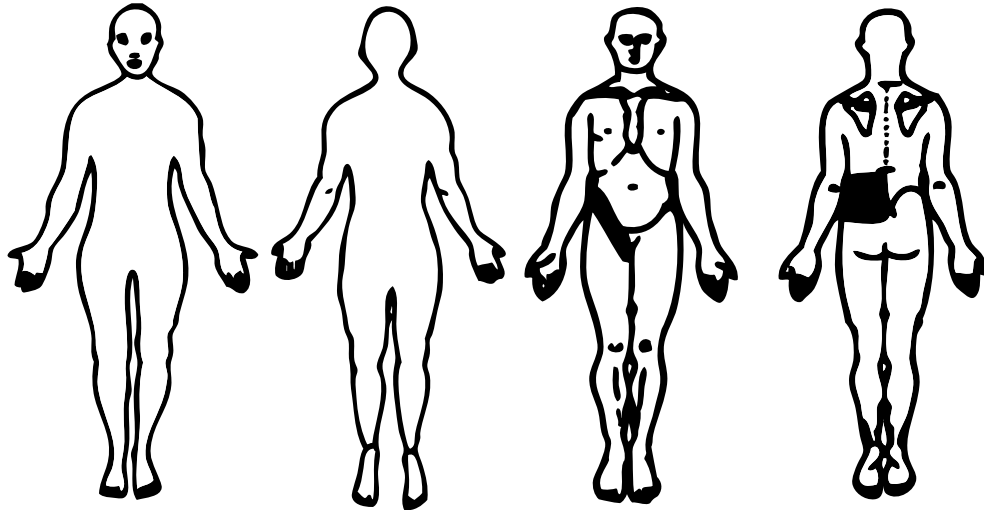
Assessment and documentation of pain are essential for evaluating the efficacy of therapy, for better understanding of the pain, for encouraging and supporting the patient and for future reference. Comprehensive pain assessment will allow determining the causes related to psychosocial factors, quality 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 if any and response to the same.

### A pain history should include the following points

- When did the pain start?
- Where is it, and does it move to any other region?
- What does it feel like (nature and severity)?
- Is it constant, or does it come and go?
- Does anything make it better or worse?
- Are there any associated symptoms?
- Is it limiting your activities?
- What do you think the pain is due to?
- What do you feel and fear about the pain (emotional impact)?
- Which analgesics have been tried and what effect did they have?
- What are your expectations of treatment?
- What is your previous experience of pain and illness?



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



Pain Diagram












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. Having a good assessment technique is the basis for effective palliative care, and prompt, appropriate management of patient's pain.

### 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. Anyone of the following scales can be used.
  - Numeric Rating Scale
  - Verbal Rating Scale
  - Visual Analog Scale
  - Verbal Descriptor scales
  - Faces Pain Rating Scale (Observation scale for kids)

## COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)

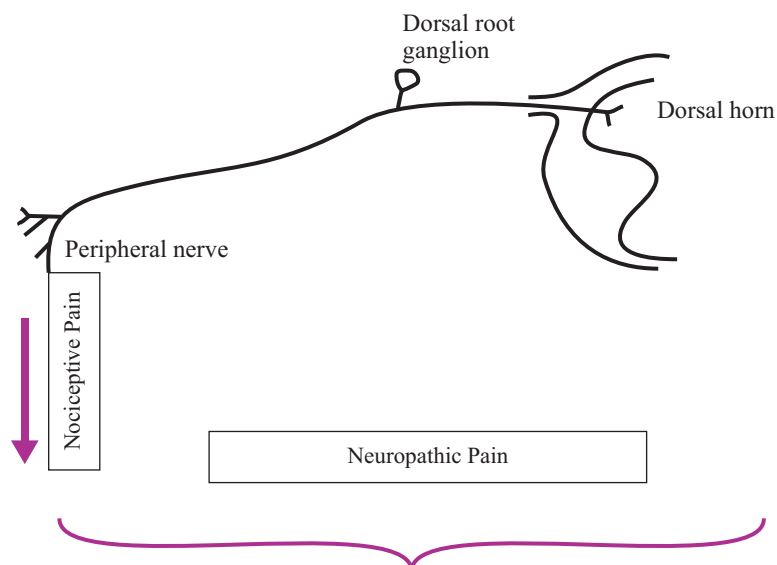
										
0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
No Pain	Minor Pain			Moderate Pain			Severe Pain			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patients unable to adapt pain.			Disabling; unable to perform daily living activities, Unable to engage in normal activities. Patient is disabled and unable to function independently.			

Mild to moderate pain may be treated with simple analgesics or NSAID. If pain is not getting controlled, then mild opioids may have to be started. If pain persists even after a mild opioid medication or if there is severe pain, then strong opioids may have to be started. Remember, opioids can cause constipation; hence a laxative also has to be given.

### Classification of Pain

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

#### Diagrammatic representation of types of Pain



Source Basic Certificate course in Palliative Medicine, IPM, Calicut

### Nociceptive Pain :

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

### Neuropathic Pain:

Neuropathic pain refers to pain arising from damage in the peripheral or central nervous system. Clinical presentations include sensations such as burning or stabbing in areas of sensory loss. Neuropathic pain could be of different forms such as Central pain, which 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.

- 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 – Experienced in the amputated limb

### Summary

Pain is one of the most important symptoms to target in palliative care. Pain assessment and management practices undertaken by health care providers have direct implications for pain control among patients. Without pain control, many other goals, for example, managing symptoms such as nausea, coping with interventions such as radiotherapy, or simply spending time with family or friends, may be unachievable.

## Chapter 6:

# Management of Pain

### Learning Objective

At the end of the session, you should be able to

- 1) Describe various drugs for managing pain
- 2) Identify the indications of acetaminophen, aspirin, NSAIDs, corticosteroids, anticonvulsants, antidepressants, and local anaesthetics used in the treatment of pain and non-pain symptoms.
- 3) Describe the use of opioids in pain management
- 4) Describe the functions of Community Health Officer in pain management.

### Group activity

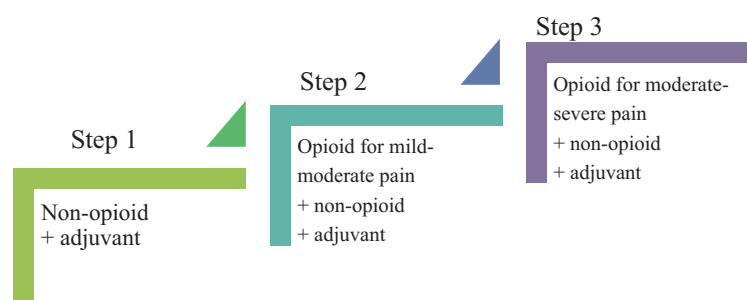
- 1) A 37-year-old lady with carcinoma breast and extensive metastases chest wall complain of pain all over the chest. She has 50% relief with Ibuprofen 400 q8h. What will you do?
- 2) A 48-year-old lady with carcinoma ovary has pain whole of the abdomen. She had adequate pain relief with Ibuprofen 400 q8h, Omeprazole 20 mg OD, Tramadol 50 mg q6h, Dulcolax 5mg bedtime. She is complaining of increasing pain for the last few days. How will you manage?
- 3) A 22-year-old man with a recent diagnosis of osteogenic sarcoma on femur complains of severe pain in the affected limb. He is already on Tab Diclofenac 50mg q8h. How will you control his pain?

### 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 per cent of patients if proper treatment guidelines for cancer pain are followed. WHO analgesic ladder is a simple protocol for treating chronic pain. To formulate a treatment plan, the nature, geography and timing of pain must be considered, as well as an understanding of the specific benefits that different analgesic or pain treatments might offer in each case.

It is important to learn the patient's view about each pain, how much it contributes to their symptom load, what factors influence it and how they would prioritize its control. A multidisciplinary approach is needed for the management of pain.

### WHO's Pain Relief Ladder



The basic principles of the analgesic ladder apply to the management of pain, whether the patient is a candidate for disease-modifying therapy or not. If a patient reports pain, the starting point can be a pharmacotherapeutic strategy based on a stepwise approach determined by the severity of 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 effective dose before switching to sustained-release opioids.
- By the Ladder:
  - In accordance with the patient.
  - Once pain control is achieved, long acting (q12h oral or q3days transdermal fentanyl) agents can replace oral preparations for better compliance and sleep.
  - Always provide appropriate breakthrough doses, i.e. 10% of total daily opioid dose dosed q1h SOS for breakthrough pain (pain that occurs spontaneously or in relation to a specific trigger in a patient whose pain is mainly stabilised).
  - Record the prescribed medications, review the effect, any associated adverse effect and titrate or modify the medications accordingly.
  - Use appropriate adjuvant analgesics at all the steps.
  - Start with lower doses in elderly patients and those with deranged kidney or liver functions.
  - Switch to another opioid when pain relief is inadequate despite dose-escalation or when associated with difficult to manage adverse effects as different opioids have different receptor agonist profile.
  - Switch to an equianalgesic dose of the another opioid, keeping in mind that recommended ratios are only a guide and that reassessment and dose modification are required.
  - When switching because of adverse effects (e.g., delirium or generalised hyperalgesia), determine the equianalgesic dose and reduce this dose by 25%.

### Points:

- By the Clock – Regular intervals, not prn/SOS
- By the Mouth – Safe, cheap and convenient
- By the Ladder – Proven method to control 90% of the 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 of pain quality etc.

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

## How to use the analgesic ladder?

### 1. STEP 1 (Non-Opioid ± Adjuvants)

Start treatment with a Non-steroidal Anti Inflammatory Drug (NSAID) (for example, Diclofenac 50 mg tid, regularly or Paracetamol 1 gm qid to q4h). If this is not adequate in managing pain in 24 hours, proceed to step 2.

### 2. STEP 2 (Step 1 + Weak Opioid)

It is important to understand the dose of analgesics in the preparations used – for example, “Paracetamol 500mg + Codeine 30mg”. Tramadol is another option. Patients should be clearly advised to take these tablets regularly and not to assess their efficacy after only a couple of doses.

### 3. STEP 3 (Step 1 + Strong Opioid)

Examples of strong opioids are morphine and Buprenorphine. 60 mg of codeine is equianalgesic to oral morphine 6-8mg. Morphine, in principle, could be started in small doses, but 10mg q4h or more may be needed while changing the prescription from Codeine 60mg to Oral Morphine. Caution should be exercised with patients who are elderly or in renal failure as active morphine metabolites are excreted by the kidney (Thus it may be necessary to decrease the dose or increase the time interval between doses.)

If the pain seems responsive to opioids, and there are no undue side effects, continue to titrate the dose upwards by not more than 25-50% every 24 hours until the pain is controlled. It is not necessary to wake the patient at night to give medication, but if pain during night or early morning is a problem, it is often helpful to increase the previous evening dose by 50-100%.

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

NSAIDs exert an anti-inflammatory action by inhibiting prostaglandin synthesis. Typical recommended doses for some of the commonly used NSAIDs are: Ibuprofen, Meloxicam, 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 not effective, an NSAID should be used rather than opioids when steroids are no longer helpful or are contraindicated. If necessary, these can be given rectally (paracetamol, naproxen or diclofenac) or subcutaneously (diclofenac or ketorolac).

## Breakthrough pain

When pain breaks through a baseline level of analgesia, for instance, while changing wound dressings, body movement, defaecation, rectal examination, manual evacuation.

Activity management – analysis and avoidance of precipitating activities if possible

## Drugs

- Sublingual Ketamine 10-25 mg (approximately 0.2-0.5 mg/kg)

- Nitrous oxide (Entomox) inhalation
- An extra dose of oral or subcutaneous Morphine sulphate 20 minutes prior to procedure (s.c injections to be used for patients unable to swallow on their own)
- Midazolam 2.5-5 mg s.c/Lorazepam 0.5 mg sublingually to alleviate anxiety.
- Sublingual Fentanyl L: Fentanyl ‘lollypops’ are expensive, but Fentanyl L 50-100 mg Sublingual route is a cheaper option.

## Management of Neuropathic Pain

### Classes of Drugs Used In Neuropathic Pain

#### Adjuvant analgesics (Co-analgesics)

An adjuvant analgesic is a drug, which is not an analgesic in its prime function but, in combination with an analgesic, can enhance pain control. E.g. anti-emetics, anti-depressants, anti-convulsant, muscle relaxant, antispasmodic, antibiotics, anxiolytics, antacids etc.

##### 1. Tricyclic Antidepressants

The mechanism of analgesic action occurs principally by 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.

##### 2. Anticonvulsants

Carbamazepine tends to result in more side effects, particularly when used in combination with other drugs. Build up doses slowly to minimise 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 less associated side effects and it is more expensive.

##### 3. Anaesthetic Agents

Ketamine: Anaesthetic agent causes dissociative anaesthesia and shown to be analgesic at sub-anaesthetic doses.

##### 4. Other Drugs

Topical Lignocaine / Bupivacaine: Topical lignocaine or bupivacaine may be useful for superficial localized areas of pain such as fungating wounds for short periods. Prolonged use may lead to skin sensitisation. 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 postherpetic neuralgia. Capsaicin is a derivative of chilli pepper and must be applied 4-5 times a day after wearing gloves. Initially, pain may increase, but perseverance may provide relief.



## 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 (i.e., 2 mg in 1 ml, 20 mg in 1 ml). An ever-increasing range of modified preparations is available (tablets, capsules, suspensions). Most are administered b.d, some o.d. There are no generic modified morphine tablets, but the pharmacokinetic profiles of different proprietary brands are broadly similar.

Morphine is metabolised mainly to morphine-3-glucuronide (M3G) and morphine-6-glucuronide (M6G). M3G is inactive, but M6G is more potent. Both glucuronides accumulate if the patient is in renal failure. This results in a prolonged duration of action, with a danger of severe sedation or respiratory depression if the dose or frequency of administration is not reduced.

### Basics of Morphine:

- No standard dose for chronic cancer pain, the correct dose is that which controls pain with minimal side effects
- Dose to be titrated for each patient
- To prescribe a laxative and antiemetic for constipation and nausea/vomiting

### Myths about Morphine:

- Only for patients with cancer
- Only when the end of life is near
- Addiction/dependence
- 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 optimised combined use of a non-opioid and a weak opioid.
2. The starting dose of morphine is calculated to give a greater analgesic effect than the medication already in use
  - a. If the patient was previously receiving a weak opioid, give 10 mg q4h or m/r 20-30 mg q 12 hours
  - b. If changing from an alternative potent opioid (such as fentanyl, methadone), a much higher dose of morphine may be needed
  - c. If the patient is frail and elderly, a lower dose could help to reduce initial drowsiness, confusion and unsteadiness, i.e., 5 mg q4h
3. Because of accumulation of an active metabolite, a lower and/or less frequent regular dose may be preferable, especially in renal failure, i.e., 5-10 mg q6h.



4. If the patient takes two or more p.r.n. doses in 24 hours, the regular dose should be increased by 30-50% every 2-3 days.
5. Upward titration of the dose of morphine stops when either the pain is relieved or intolerable or undesirable effects supervene. In the latter case, it is generally necessary to consider alternative measures. The aim is to have the patient free of pain and mentally alert.
6. Because of poor absorption, m/r morphine may not be satisfactory in patients troubled by frequent vomiting or those with diarrhoea or an ileostomy. M/r morphine should be used with caution if there is renal impairment.
7. Supply an antiemetic in case the patient becomes nauseated, such as haloperidol 1.5mg stat & prn
8. Prescribe stimulant laxatives. Adjust the dose as necessary. Suppositories and enemas remain necessary in about 1/3rd of patients. Constipation may be more difficult to manage than pain.
9. Warn patients about the possibility of initial drowsiness.
10. If swallowing is difficult or there is persistent vomiting, morphine may be given PR by suppository; the dose is the same as PO. Alternatively give 1/2 the oral dose by injection, or 1/3rd as diamorphine, preferably by CSCI.
11. For outpatients, write out the drug regimen in detail with time, name of drug and amount to be taken and arrange for follow-up.

#### **Ordinary (normal/ immediate-release) morphine tablets or solution**

- Morphine is given q4h regularly 'by the clock' with q1h p.r.n. doses of an equal amount
- After 1-2 days, adjust the dose upwards if the patient still has pain or using two or more p.r.n. doses per day
- Continue q4h regularly with q1h p.r.n. doses of an equal amount
- Increase the regular dose by 30-50% every 2-3 days until there is adequate relief during each 4 hour period

A double dose at bedtime obviates the need to wake the patient up for a 4 hourly dose in early morning

#### **Morphine Side Effects:**

Common opioid side-effects and their management

- 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 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, sweating: Try opioid rotation or 5HT3 antagonists (e.g. ondansetron, granisetron).

### Writing prescriptions for Morphine:

1. Name of drug, strength, route, dose and frequency .
2. Number of days for which the drug is prescribed.
3. Drugs that would have to be taken along with it.

### Steps in Morphine Trial

1. Clinical assessment to rule out opioid resistance, pain and contraindications to intravenous morphine (bronchospasm)
2. Secure an intravenous access
3. Check vital signs (Blood pressure, Pulse, Respiration)
4. Start slowly with 10 mg metochlopramide followed by 1.5 mg morphine intravenously (dilute 1 ml of 15 mg morphine in 9 ml distilled water to get a final concentration of 1.5 mg morphine per ml)
5. Reassess pain after 10 minutes
6. Repeat intravenous bolus dose of 1.5 mg morphine every 10 minutes till the patient is either pain-free or drowsy
7. Estimate the total dose of intravenous morphine required for pain relief
8. Start the patient on the nearest dose of oral morphine 4th hourly (for instance, if a patient requires 9 mg morphine intravenously for pain relief, start on oral morphine 10 mg q4h)  
  
Note: Such estimate need not always be optimum. In a small percentage of patients, the oral morphine requirement (per dose) can be anywhere from 1/3rd to twice the initial dose
9. Reassess the next day for dose adjustment
10. For a quicker response, pethidine may be administered every 5 minutes. For dilution, use 1 ml of 50 mg pethidine solution mixed in 5 ml of distilled water to get a final working concentration of 10 mg per ml. Conversation ratio of intravenous pethidine to morphine is 10:1 such that 100 mg pethidine is equivalent to 10 mg morphine.

### Morphine - what to be careful about

Quite often, the hospitals and dispensaries neglect to provide full details about morphine that is needed by most cancer patients to overcome pain. The following details should be kept in mind before starting on a morphine treatment regimen:

- Painkillers such as morphine should 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 to avoid waking up from sleep to take medicine.
- Morphine does not cause acidity or heartburn so that it can be taken before or after food.
- Morphine may induce constipation. Therefore, the medicine for constipation too has to be taken along with morphine on doctor's direction.

- Morphine may induce vomiting initially in some patients. However, vomiting may not last a week or more. It is advisable to take medicine to control vomiting while starting on a morphine regimen.
- If the patient is drowsy or delirious after taking morphine, it could be due to overdose. Stop the next dose and inform the doctor. An identical procedure 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

### Opioid conversion tips

- Calculate the rescue dose: Prescribe 10% of the total daily opioid dose as an immediate-release formulation.

### Opioid adjustments:

1. Calculate the total oral 24-hour opioid taken by adding the amount of the sustained-release and immediate-release rescue doses.
2. Divide total daily dose into appropriate intermittent doses based upon the specific opioid dosing intervals.
  - Changing to another oral opioid:
    1. Calculate the total daily dose of current opioid (add the long-acting and breakthrough doses).
    2. Calculate the equianalgesic oral dose of the alternative opioid.
    3. Divide total daily dose of the alternative opioid into appropriate intermittent doses based upon the opioid specific dosing intervals.
    4. Modify by reducing the dose by 25%-50% for incomplete cross-tolerance.
  - Changing an oral opioid to its IV/SQ route:
    1. Calculate the total amount of 24-hour oral opioid taken (add regular and breakthrough doses).
    2. Calculate the equianalgesic total daily parenteral dose (e.g. divide the oral 24-hour dose of morphine by 3 to get a 24-hour dose of IV morphine).
    3. Divide the equianalgesic dose by 24 to get the hourly drip-rate.
  - Changing an oral or IV opioid to transdermal fentanyl:
    1. Calculate the total opioid dose (add regular and breakthrough doses).
    2. Calculate the equivalent total daily morphine dose.
    3. Determine the equi-analgesic dose of transdermal fentanyl using the patch conversion

### Management of a patient with pain.

- Assess pain characteristics 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 nonpharmacological 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 for pain management.
- Assist the patient in making decisions about selecting a particular pain management strategy.
- Teach the patient and family about using nonpharmacological 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 30min/hr.
  - 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 min/hr. Special attention needs to be given to preventing 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. Many health insurance programs will not reimburse for the cost of therapeutic 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, the technique works to interrupt pain transmission by "closing the gate". This the approach requires training and practice.
- **Transcutaneous electrical nerve stimulation (TENS):** TENS requires the application of two 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 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, imagining a peaceful scene, as much as possible.
- Explain the importance of drug compliance in pain management and discourage to stop any self-prescribed medications
- Teach the family how to give oral Morphine.
- Teach the patient and family about the rectal route for Morphine administration in patients who can't take 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 Analgesic at home (Eg. 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.

## Chapter 7:

# Symptom Management

### Learning Objective

At the end of the session, you should be able to

- 1) Demonstrate an understanding of the causes of common symptoms in palliative care
- 2) Demonstrate nursing management of dyspnea, cough, urinary problems, oral problems, nausea, vomiting, diarrhoea and constipation in palliative care practice

### Group activity

Mr Kumar 55-year-old beedi worker, a father of three children, was diagnosed with lung cancer. His disease was in an advanced stage spread locally, and his general condition was very poor to tolerate chemotherapy. He had a course of palliative radiotherapy to his chest. He presented with complaints of severe dyspnoea before treatment, which has worsened after the treatment. The patient had been bedbound and anxious to move since any kind of exertion, worsened his breathlessness.

1. What must be the likely problems that made Mr Kumar think he would be unable to get out of bed?
2. What physiological response would fear to create that would contribute to his breathlessness?
3. How can you help the family understand how the disease process will progress so that they can be supportive of Mr Kumar?

### BREATHLESSNESS /DYSPNOEA/BREATHING DIFFICULTY

Breathlessness is common among patients suffering from many long term illnesses relating to lungs, heart, kidney and so on.

<u>Accompanying difficulties</u>	<u>Assessment of Intensity of breathlessness</u>
Cough	Light:-due to hard work, or climbing upstairs
Fever	Moderate:-breathlessness while walking
Chest congestion,	Severe:-breathlessness even at rest
Chest pain,	
Swelling in the feet and face	
Enlargement of abdomen	
Accumulation of phlegm in the throat.	

#### Causes of Breathlessness

<u>Related to Cancer</u>	<u>Unrelated to cancer</u>
<ul style="list-style-type: none"> <li>• Cancer of the lungs, trachea (windpipe), or throat</li> <li>• Cancer has spread to other parts of the body.</li> <li>• Distension (enlargement) of the stomach due to either cancer or fluid.</li> <li>• Anaemia related to cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Asthma</li> <li>• Infections: Tuberculosis, Pneumonia etc</li> <li>• Heart ailments</li> <li>• Tobacco induced diseases</li> <li>• Plural effusion( fluid formation in the lung cavity) or Pneumothorax (air invasion in the lung cavity)</li> </ul>



### Useful questions when assessing breathlessness

Air hunger	Do you feel like you are not getting enough air to breathe?
Activity	Do you feel breathless when you are at rest? Do you feel breathless when you perform some activity? What activity makes you breathless?
Position	Do you get relief when you assume a particular position?
Diurnal variation	Is the breathlessness worse at some particular time of the day?
Anxiety	Is your breathlessness precipitated by fear and anxiety? Do you feel anxious when you are breathless?
Associated symptoms	Cough Pain Fever Edema Rattling Cyanosis Pallor Anxiety Abdominal distention

OR

Onset	Quality
<ul style="list-style-type: none"> <li>Has it come on suddenly or is, has it been long term? Sudden onset can be due to acute causes, e.g. pulmonary embolus, bronchial obstruction.</li> <li>Is it associated with stridor or signs of superior vena cava obstruction (facial swelling or distension of upper body veins)?</li> <li>Is the person in the terminal phase? Provoking/relieving</li> <li>Does it occur at rest?</li> <li>What brings it on - exertion/ position/ environmental factors?</li> <li>What non-drug measures are being used and do they help?</li> <li>What medications are being used and what effect do they have on the breathlessness?</li> <li>If oxygen is being used, does it help the sensation of breathlessness or otherwise make the patient better?</li> <li>Are there other symptoms causing discomfort?</li> </ul>	<ul style="list-style-type: none"> <li>What does it feel like?</li> <li>Verbal descriptors can be illustrative, e.g.: <ul style="list-style-type: none"> <li>“I feel out of breath.”</li> <li>“I cannot get enough air.”</li> <li>“I cannot take a deep breath.”</li> <li>“My breathing is shallow.”</li> <li>“My breath does not go all the way out.”</li> <li>“My breathing is heavy.”</li> <li>“My chest feels tight.”</li> <li>“My breathing requires more work/effort.”</li> <li>“I feel too tired to breathe.”</li> <li>“I feel that I am suffocating.”</li> <li>“I feel that my breathing is rapid.”</li> <li>“I am gasping for breath.”</li> </ul> </li> </ul>
Understanding	Severity
<ul style="list-style-type: none"> <li>What is your understanding of your breathlessness and its causes?</li> <li>What does your breathlessness mean to you and your family?</li> <li>What is your goal for this symptom?</li> </ul>	<ul style="list-style-type: none"> <li>How bothered is the person by their breathlessness? At best? At worst? On average?</li> <li>On a scale of 0 (not at all breathless) – 10 (worst imaginable breathlessness), how does the person rate their breathing sensation over the past 24 hrs?</li> <li>Exercise tolerance: how much exertion can the person do before becoming short of breath?</li> </ul>

## Management

For the purpose of management, the severity of breathlessness is categorized as

1. Breathlessness on exertion
2. Breathlessness at rest
3. Terminal breathlessness

## Pharmacological Management

Possible cause	Management
Asthma	Bronchodilators, corticosteroids, physiotherapy
Pulmonary oedema	Diuretics, diamorphine/ morphine
Pneumonia	Antibiotics, physiotherapy
Pneumothorax	Chest drainage, oxygen

## Non-Pharmacological Management

- Positioning - sit the patient up, 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. Consider Physiotherapy/ Occupational therapy / referral.
- Controlled Breathing: Aim to reduce the rate of breathing (breath in, blow out).
- Encourage diaphragmatic (“use lower chest muscles”) breathing 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.
- Massage of 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.
- Dyspnoea is frightening to patient, family and staff. Reassurance and explanation are vital parts of the treatment, whatever the cause.
- Modification of lifestyle, breathing retraining and relaxation may be beneficial if instituted early enough.
- Consider referral to physiotherapist or occupational therapist
- A portable/table fan directed onto the face often eases dyspnoea.
- Good oral care is important if there is persistent mouth breathing.
- Humidified oxygen may help acute dyspnoea but should be used alongside other measures, and its use reviewed regularly.
- Long term oxygen therapy for chronic respiratory illness should only be instigated by respiratory physicians.



### General guidelines for managing any symptoms in palliative care

1. Listen attentively. Be a good listener.
2. Do not consider the patient's problems as 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.
7. Do not force the patient to talk.

### COUGH

A cough is a common reflex action that aims to clear the throat of mucus or foreign irritants. Persistent coughing can cause anorexia, nausea and vomiting, musculoskeletal pain, fracture of rib, stress incontinence and exhaustion.

#### Aim

To relieve symptoms and associated distress.

#### Rationale

Coughing disrupts sleep, nutrition, social life, and leads to exhaustion.

#### Causes

- Symptoms of cancer that can cause mechanical irritation in the lungs and adjacent areas
- Chest infection from cancer or other debilitating conditions
- Treatment regimen (radiotherapy-induced fibrosis)

**Disease conditions such as asthma, heart failure, chronic airways disease**

**Other causes such as postnasal drip, smoking**

#### Types of Cough

- Wet and productive cough. When a patient might not produce sputum when too weak to cough effectively.
- Dry and non-productive cough.

#### Management

- Assess for a treatable cause
- Ensure a suitable environment – comfortable temperature, humidification
- Soothing warm drink or lozenges
- For productive cough– encourage the expulsion of secretions, physiotherapy and postural drainage.
- Drugs -cough suppressants expectorants, anti-tussive, bronchodilators etc.
- Opioids are the drugs of choice in the symptomatic management of cough in advanced diseases. Codeine is commonly used as a cough suppressant.
- Oral Morphine is also effective.

- Corticosteroids are helpful in controlling radiotherapy-induced cough and cough due to lung congestion by tumour

### Nursing Care

- Assess whether productive or non-productive cough such as the production of sputum and nature of it.
- Treat underlying diagnosis such as infection
- Assess the environment of the patient. Is it a smoky room, cold room, dry atmosphere?
- Provide soothing warm honey drink or lozenges
- Inhalation of eucalyptus oil-infused steam for productive cough.
- Physiotherapy for productive cough: With the patient lying on their side, support the abdomen with a pillow, blow out sharply three times, hold breath, then cough.
- Change position and provide support.
- Humidification
- Postural drainage
- Pharmacological - Provide cough suppressant or expectorant as appropriate, demulcents such as non- opioid antitussive, opioids and bronchodilators.

### URINARY PROBLEMS

Urological problems like voiding dysfunction are a major challenge to many of the patients with neurological disability, urogenital cancers, patients on dialysis, and geriatric illness patients. If not managed properly, these uncontrolled symptoms lead to psychological distress, with limited acidity of daily living.

#### Diseases related to urinary system:

1. Bladder Cancer
2. Prostate cancer
3. Urethral Growth
4. Post-surgical conditions of the urinary system
5. Problems related to spinal injury
6. The weakness of bladder muscles and sphincter muscles
7. Problems related to old age
8. Infection
9. Bladder outlet obstruction
10. Stricture of the urethra

#### Clinical features

Dysuria, hesitancy and retention of urine, increased frequency of urination, incontinence, pyuria, haematuria, polyuria, oliguria

#### Assessment of clinical features

- 1) Pain: onset of pain (before, during or after passing urine)
- 2) Colour: dark coloured with the presence of blood, pus, faecal matter (in rectovesical fistula)

- 3) Passing air in urine (Pneumaturia)
- 4) Smell: fruity smell (ketosis), foul smell (infection), faecal smell (fistula)
- 5) Local examination of perineum and genitourinary tract
- 6) Incontinence: (assess nature of incontinence – stress, urge, overflow or total)
- 7) Fistula: site

### **Retention of urine**

- Time of the last voiding
- Drug (medicine) history
- Discomfort and pain
- Distension of lower abdomen

### **Psychological problems**

- Financial problems
- Social problems
- Spiritual problems
- Sexual problems
- Problems associated with dependence and privacy

### **Common urinary symptoms:**

#### **1. Urinary incontinence**

Urinary incontinence is defined as the involuntary urination or loss of urine from the bladder.

##### **a) Stress incontinence**

Stress incontinence is the involuntary loss of urine when the intra-abdominal pressure increases. Actions such as coughing, sneezing and laughing can cause urine leakage in patients with stress urinary incontinence.

##### **Assessment question:**

1. Do you leak urine when you laugh, sneeze, cough or lift something heavy?
2. Do you leak urine when you exercise?

##### **b) Urge incontinence:**

Urge incontinence is a sudden, strong urge to urinate, resulting in involuntary urination before reaching the toilet. It usually occurs in the over-reactive bladder, where the sudden strong urge to urinate occurs even with the bladder being half full.

### **Assessment questions**

1. Do you often feel a sudden urge to urinate and then rush to the toilet?
2. Do you plan to stay near a bathroom when you work or perform other activities?
3. Do you often feel nervous because you think that you will lose your bladder control?

**c) Overflow incontinence:**

Overflow incontinence occurs when the bladder emptying is incomplete, resulting in leakage of urine with or without feeling the urge to void. It usually happens in case of obstruction of the urethra. E.g. Prostate Enlargement.

**Assessment question:**

1. Do you often feel that you have not completely emptied your bladder?
2. Do you find yourself soiling the underwear frequently?

**d) Functional incontinence:**

Functional incontinence occurs when there is no problem with the urinary tract, but the person is incontinent due to other ailments such as cerebral palsy, dementia, arthritis, etc.

**Assessing functional incontinence**

1. Ruling out other types of incontinence
2. Identify underlying disease leading to incontinence

**e) Total incontinence:**

Continuous leakage of urine.

**f) Mixed incontinence:**

Combination of two or more types of incontinence

**2. Hesitancy:**

Hesitancy is defined as the difficulty in initiating the urinary stream or delay in the urinary stream. It is usually seen in benign prostatic enlargement.

**3. Frequency:**

Urinary frequency is defined as the frequent micturition more than the normal occurrence in day or night or both day and night. Typically, it is more than eight times per day with the volume being less than 200mL per voiding. The frequency may be accompanied by an urge to urinate.

**4. Polyuria:**

Polyuria is defined as frequent micturition more than the normal occurrence with a normal amount of urine at each voiding. Thus, the overall urine output exceeds 2 to 3 litres over 24 hours.

**5. Poor stream:**

A weak or slow stream of urine while voiding

**6. Intermittent stream:**

Difficulty in maintaining a steady stream of urine while voiding or intermittent stream of urine while voiding.

**7. Dysuria:**

Dysuria is defined as painful or burning micturition.

**8. Oliguria:**

Oliguria is defined as urine output less than 400mL/day

**9. Anuria:**

Anuria is defined as urine output less than 50mL/day

#### 10. Nocturia:

Nocturia is defined as the need to wake up one or more times to urinate.

#### 11. Renal colic:

Renal colic is characterized by sudden onset flank pain that radiates to the abdomen laterally and/or to the groins. The pain is also characterized as constant pain with colicky episodes of pain with increased intensity.

#### 12. Pyuria:

Presence of pus/ white blood cells in the urine.

#### 13. Hematuria:

Presence of blood in the urine

#### 14. Urinary retention:

Is defined as the inability to voluntarily void urine.

#### 15. Bladder spasm:

It is defined as the sudden, involuntary contraction of the bladder usually associated with pain and urge to urinate.

Intake output chart that can be used at home:

Name of the patient:				
Date:				
Input			Output	
Time	Type of fluid given	Volume (mL)	Time	Volume (mL)

#### General management of urological problems

- Ensure adequate fluid intake.
- Change catheter every 2-4 weeks (silicone coated catheters can be placed for long term)
- Avoid traction on a catheter while turning in bed
- Prevent reflux of urine into the bladder
- Ensure good perineal care

#### Incontinence of Urine

- Treat for pyuria or infection
- Give bedpan when the patient asks for it or assist the patient in reaching the bathroom.
- Encourage the patient to pass urine frequently so that he/she develops the habit of voiding once in 3-4 hours
- Intake of water during the day can be increased so that frequent voiding in the night will not disturb sleep.
- The perineal area should be kept clean

- Assess whether the patient can pass urine. If not, catheterization should be done especially for cases of total incontinence and retention
- Perineal exercise to tone the muscles
- Give hot water fomentation on the lower abdomen or a wash with warm water.
- Stimulation by sitting patient next to running water.
- The patient should be given enough time to empty the bladder completely

### Group activity

1. Miss Emily Mathews is a 16-year-old school-going woman who is getting high marks in her studies. She has a known case of Osteogenic sarcoma in her right femur and was planned for amputation after chemotherapy. She has been undergoing high dose Methotrexate therapy for the treatment of her disease. She has attempted to continue her schoolwork but has had consistent problems with nausea and vomiting secondary to her chemotherapy. She lives with her parents and three younger brothers. Both of her parents work, her mother as a daily worker and her father as an auto driver. When you first see her, she appears thin and dehydrated.
  1. Identify the symptoms of dehydration.
  2. What part might fear to play in Emily's nausea and vomiting?
  3. Priorities her needs according to the severity of her disease.
  4. How do you treat this vomiting in palliative care?
  5. Is she a candidate for palliative care?
2. Ravi is a 75-year-old gentleman with a history of Ca rectum which is thought to be in remission. Normally he would walk 10 km/day but recently had a foot injury which prevents him from walking. He lives with his wife in their home and has two grown children who do not live with him. They receive money from the government every month. Recently he has been experiencing episodes of constipation and is having tests to determine what the cause might be. It has been determined that he has had a recurrence of his cancer, and this news is not shared with him. A surgical consultation has been sent.
  - 1) What will be your plan about communicating the recurrence to Mr Ravi?
  - 2) What measures can be taken to relieve his constipation?

### Common problems in the Oral Cavity

A clean, fresh, comfortable mouth is very important for patients. It helps with comfort, communication and feeding. Many people with head and cancer have problems with their mouth. This can be related to the disease itself, to the treatments or other problems. Many patients will need help with their mouth care.

### ORAL CANDIDIASIS/THRUSH

#### Candida infection of the oral cavity.

<u>Features</u>	<u>Causes</u>
<ul style="list-style-type: none"> <li>• White adherent patches</li> <li>• Coated on the tongue</li> <li>• May appear red and ulcerated</li> </ul>	<ul style="list-style-type: none"> <li>• Corticosteroids</li> <li>• Antibiotics</li> <li>• Diabetes mellitus</li> <li>• Dry mouth</li> <li>• Immune suppression</li> </ul>

- Patients may or may not have oral symptoms like pain and difficulty in swallowing (oesophageal Candidiasis).
- Usually manifest as off white patches/plaques (pseudomembranous Candidiasis) or reddened, inflamed oral mucosa (erythematous Candidiasis).

### Management

Treatment involves the management of infection, symptoms and cause of infection

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

### XEROSTOMIA

- The subjective sensation of dry mouth.
- May be associated with loss of taste, difficulty in swallowing, speaking or chewing.
- Causes
  - Infection: Candidiasis
  - Drugs: Anticholinergics, Anti-depressants, opioids
  - Radiotherapy
  - Dehydration
  - Mouth breathing
  - Anxiety - Treatment

### Assessment questions for xerostomia

- Does oral dryness bother you?
- Do you need to take increased fluids?
- Is your mouth painful?
- Do you experience altered taste sensations?
- Is it difficult to speak or swallow?
- Do you use tobacco? What type? How much?
- Are you on any medications? Including over the counter prescriptions?

### Management

- Treat underlying infection, such as thrush
- Review and alter unnecessary current medications
- Stimulate salivary flow
- Replace loss of secretions with saliva substitutes
- Protect teeth with hourly mouth care
- Rehydrate with ice chips
- Modify diet. Consider chewing gums, pineapple, mild citrus drinks, soda water and normal saline
- Consider saliva substituent (costly)



## HALITOSIS

It is foul or unpleasant breath

### Determine the cause:

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

### Non-pharmacological interventions

- Meticulous oral hygiene
- Clean and soak dentures
- Ensure adequate fluid intake
- Flavoured sweets, e.g. mints

### Medical Management

- Anaerobic infection of gums - oral metronidazole 400mg BD
- Gastric fluid - Metoclopramide 10mg TDS or domperidone 10 to 20mg QDS
- Anaerobic infection of lungs - systemic metronidazole
- Antiseptic mouthwash - Chlorhexidine 10ml QDS
- Debriding agents if indicated
- Preparing solution:
  - Ascorbic acid (Vit C) - 250mg (1/4 of gram tablet) effervescent on the tongue QID.
  - Hydrogen peroxide mouthwash 3% - 10 ml in half a tumble of water BD/TDS.
- Preparing the saline solution:  
Take 500ml of drinking water and add one teaspoon of salt. Boil, cool and keep covered until needed.

### Nursing Care

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

- Regularly apply a simple vegetable oil, such as coconut, to the lips. A few drops can also be smeared on the tongue. Often it is best to ask the patient to do this himself.
- Frequent sipping of water can also be helpful, so ensure the cup is nearby.

### Troubleshooting

- If the dry mouth is severe, consult with your doctor, who may help to adjust any drugs to help.
- If there are white cur-like patches, especially with pain on swallowing, there is likely to be a fungal infection, and the doctor will prescribe some specific treatment.
- If pain persists, you will need general painkillers, which your doctor can prescribe.
- If there is an unpleasant smell, there may be a bacterial infection, and your doctor may give antibiotics as tablets or metronidazole solution.

### Oral Hygiene in Palliative Care

#### Goals:

- To encourage oral care, thus reducing the risk of infection and consequent discomfort.
- Discuss the treatment of dry mouth (xerostomia), sore mouth and coated tongue.
- Explain therapeutic management, interventions and treatment of above symptoms.

### Routine mouth care

- Recommended daily assessment
- Brush and rinse mouth at every 12-hour interval
- Soak dentures overnight
- Apply lip balm for cracked lips

### Dependent patients

- 2-4 hourly mouth care (Assess individually)
- Use of soft brush, foam stick applicator or glove and gauze
- Use of syringe for gentle mouth wash
- Avoid lemon as it over stimulates salivary glands and glycerine as it dehydrates

### Nausea and vomiting

Nausea and vomiting are symptoms, which can cause patients and their relative's 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 illness like cancer, problems in the food pipe and stomach/ bowel result in severe vomiting and nausea many times. 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

## Causes

<b><u>General</u></b>	<b><u>Disease-related</u></b>
<ul style="list-style-type: none"> <li>• Motion sickness or seasickness</li> <li>• Early <u>stages of pregnancy</u></li> <li>• Emotional stress (such as fear)</li> <li>• Gallbladder disease</li> <li>• Food poisoning</li> <li>• Overeating</li> <li>• A reaction to certain smells or odours</li> <li>• <u>Heart attack</u></li> <li>• Concussion or brain injury</li> <li>• Ulcers</li> <li>• Bulimia or other psychological illnesses</li> <li>• Gastroparesis or slow stomach emptying (a condition that can be seen in people with diabetes)</li> <li>• Ingestion of toxins or excessive amounts of alcohol</li> </ul>	<ul style="list-style-type: none"> <li>• Obstruction in the movement of food and water through the oesophagus, stomach and the intestine due to cancer.</li> <li>• Medication-induced vomiting (Chemotherapy, Radiation)</li> <li>• Some forms of cancer</li> <li>• Brain tumour</li> <li>• Certain medications like morphine etc</li> <li>• Infections</li> <li>• Ascites</li> <li>• Constipation</li> </ul>

## Assessment

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 factors	Smell, food and other activities
Associated symptoms	Headache, Abdominal pain, Fever, Heartburns, Abdominal distention, Hiccups, Constipation, Loose stools, Signs of dehydration
Sensorium	Conscious/Semi conscious/Unconscious Oriented/Disoriented/Calm/Agitated/Restless
Vestibular disturbances	Do you feel dizzy?
Drugs	What medications are you currently on? Recent chemotherapy or radiotherapy.
If on NG tube	Amount feed Frequency of feeding Type of feed
Examination	a) Per-Rectal digital examination if constipated b) Blood pressure and Heart rate recording

### Management:

- Prescribe the most appropriate antiemetic stat, regular and SOS.
- Titrate the dose to the effect.
- If no effect switch or add another anti-emetic from a different class. Review the choice and route of anti-emetic.
- Constantly review for effect and side-effects.
- Consider pre-emptive use of anti-emetics when starting opioids.

### Consider the route of administration of medication, since-

- Persistent vomiting may reduce gastric emptying with a resultant decrease in 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 (pocket size syringe driver) rather than bolus injections which are more apt for a single episode.
- Anti-emetics in suppository or tablet form can also be administered rectally.

### Nursing Management

1. Try to provide care to the patient in a well-ventilated room. Put on the fan if needed.
2. Ensure that the patient is taking medicines as prescribed.
3. Avoid smells that cause nausea, for, e.g., the smell of cooking, the smell of phenol, Dettol etc.
4. Keep a bowl for vomiting close by.
5. Give small portions of food at frequent intervals instead of big meals at one time
6. 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.
7. Try to make the patient sit up while eating and let him not lie down immediately after food
8. Give the patient the food that he prefers
9. Make sure that the patient takes plenty of fluids
10. Make sure that medication prescribed for vomiting, is taken in proper dose at the proper time.
11. Try ginger, such as candied ginger or ginger tea. Real ginger—not ginger flavouring—helps to reduce nausea.
12. When the patient is feeling better, begin eating clear soups, mild foods, and liquids until all symptoms are gone for 12 to 48 hours.
13. Don't force the patient to eat too much at once. Stretching the stomach may worsen nausea and cause vomiting
14. Avoid milk, alcohol, caffeine, carbonated beverages, and most fruit juices. Milk may increase feelings of nausea.
15. Explanation and reassurance about the possible causes and about the investigations and treatments that may be necessary.
16. Odour: avoid strong smells (e.g. food, infected/necrotic tumours, etc.), use deodorisers.
17. Environment: space, air movement.
18. 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; o crushed ice cubes / frozen drinks such as coke and fruit juice. Ginger is a useful antiemetic, in ginger tea or crystalline form.

19. Good oral hygiene (especially after vomits);
20. Relaxation / distraction techniques;
21. Acupuncture and hypnosis may have a role for practitioners who have these skills;
22. Position: sitting upright, head of the bed to relieve pressure on the abdomen;
23. Relaxation therapy

### Signs of dehydration

- Increased thirst	- Skin that withdraws too slowly after being punched
- Dry mouth	- Weakness
- Swollen tongue	- Dizziness
- Sunken eyes	- Palpitations (feeling that the heart is jumping or pounding)
- Too little urine	- Sluggishness
- Dark colour urine	- Fainting
- Confusion	

### Home Care Education

- Encourage small and frequent feeds.
- Encourage the patient to choose the menu.
- Explain 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 10-12mg/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 due to constipation consider laxative or enemas as necessary.
- Educate the patient and family about taking the medication at the correct time  
(Eg: 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 common in chronically ill patients, especially the bedridden.

### Key Principles

- “Prevention is better than cure”.
- ALWAYS prescribe a laxative when commencing an opioid analgesic.

- Careful assessment of bowel pattern is crucial, e.g. the report of a bowel movement does not exclude constipation.
- In palliative care patients, the treatment of constipation is different from that in healthy, active people.
- Even with inadequate oral intake, the bowel produces its own ‘bulk’ and constipation can occur.
- Remember ‘diarrhoea’ can be overflow with constipation – abdominal X-ray is very helpful.
- Towards the end-of-life stage, active management of constipation may be unnecessarily intrusive and burdensome and can be curtailed (an exception may be the agitated patient with a full rectum).

## Causes of Constipation

<u>General</u>	<u>Disease-related</u>
Lack of exercise Lack of physical activity Confusion, sedation Sense of guilt as the patient has to depend on help even for his basic needs. Lack of privacy Fatigue Stress	Pain Certain health problems like Parkinson's disease, <u>hypothyroidism</u> Fatigue Intestinal obstruction (Problems in the GI tract that compress or narrow your colon and rectum can cause constipation.) Spinal cord compression Dehydration
<u>Nutritional</u>	<u>Drug-induced</u>
Changes in the type of food. Decreased intake of food and water Lack of adequate fibre in food Low residue diet	Opioids (morphine, tramadol, codeine etc.) Antidiarrheal Anti-depressants
<u>Symptoms of Constipation</u>	<u>Assess for the following</u>
<ul style="list-style-type: none"> <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 style="list-style-type: none"> <li>• how often patient have a bowel movement</li> <li>• how long patient had symptoms</li> <li>• what the stools look like and whether the patient has blood in your stool</li> <li>• eating habits</li> <li>• level of physical activity</li> <li>• the medicines taken</li> </ul>

## Assessment

Bowel pattern	How regular are your bowel patterns? (Before the onset of illness and now)
Dietary pattern	Amount of water consumed per day in glasses Inclusion of food rich in fibres like green leafy vegetables
Consistency	Hard stools or Soft stools
Duration	How long have you been having difficulty passing stool? 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/Excoriations/Tumours Haemorrhoids
Examination	Per-Rectal digital examination

## Examination

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

## Management

1. Correct any correctible 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 laxative 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 polyethene glycol (PEG). However, lactulose can taste unpleasant and cause bloating.
  - For patients with opioid-induced constipation, after a trial of first-line recommended stimulant laxatives and osmotic laxatives, methylnaltrexone may be helpful.
  - 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) or bleeding (thrombocytopenia), or when there is rectal/anal disease.
  - 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.



## Nursing Care

- Assess the usual pattern of elimination; compare with the present pattern. Include size, frequency, colour and quality of stool.
- Ensure privacy for the patient and provide commode or bedpan, if required.
- Ensure patient is taking medicines as per the prescription.
- Exercising every day may help prevent and relieve constipation. Exercise the body according to the patient's ability. Even bedridden patients should be given some light exercises.
- Evaluate reliance on enemas for elimination
- Evaluate usual dietary habits, eating habits, eating schedule and liquid intake.
- 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
- Teach on active and passive exercises
- High fibre food (e.g., raw fruits, fresh vegetables, whole grains) to be taken with adequate fluids
- Consider enema and suppositories if the patient is no longer able to tolerate oral medications, or they have become ineffective.
- Digitally removal of a faecal impaction as ordered patient is no longer able to tolerate oral medications, or they have become ineffective

## Home care education:

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

## Diarrhoea

Loose, watery stools occurring more than three times in one day

Causes	Symptoms
<ul style="list-style-type: none"> <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 tumor/ RVF</li> <li>• Faecal incontinence, loss of sphincter control</li> </ul>	<ul style="list-style-type: none"> <li>Urgent need to go to the toilet</li> <li>Thin or loose stools/ 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>Generally body weakness and tiredness</li> <li>Nausea and vomiting</li> <li>Bloating and Cramps</li> </ul>

### Assessment

Bowel pattern	How regular are your bowel pattern?
History of constipation	Have you been having difficulty passing stool before this? When was the last time you passed stool to your satisfaction?
Dietary pattern	Any recent change in food consumed?
Consistency	Hard stools or Soft stools or watery stool or mucoid stools
Duration	When did the diarrhoea start? How long have you been having diarrhoea?
Frequency	Number of episodes per day
Associated symptom	<ul style="list-style-type: none"> <li>• Vomiting</li> <li>• Abdominal pain or cramps Abdominal distention, Fever</li> <li>• Signs of dehydration</li> </ul>
Drugs	What medications are you currently on? How frequently are you taking laxatives?
Examination	<ul style="list-style-type: none"> <li>• Per-Rectal digital examination Blood pressure and Heart rate</li> <li>• Perianal skin condition</li> </ul>

### Nursing Care

- Assess the patient's normal bowel elimination pattern
- Determine the cause for incontinence
- Perform manual check for 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 under pads
- Assess perineal skin integrity
- Correct any obvious factors related to assessment
- Notify the physician if it is of the bacterial cause
- Educate 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 diet at least 3 litres/day which includes electrolyte drinks
- Wash the perineal areas after each evacuation with soap and water, dry thoroughly.
- Treat any perineal irritation with moisture barrier ointment.
- Discourage the use of 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 diarrhoea resolves
- While cooking and storing food

The following rules when preparing food can also help prevent diarrhoea:

- Wash hands before and after taking food
- always put foods that could spoil in the fridge
- use only boiled and cooled water.
- ensure that meat is cooked thoroughly
- avoid eating raw meats, fish, and shellfish unless you are sure that they have been freshly prepared and are from a reliable source.

### Home care education

1. Explain to the patient about the signs and symptoms of dehydration.
2. Explain about ORS preparation
3. Acknowledge the carer's burden and sharing the work will minimise the burden
4. Explain the importance of maintaining skin integrity

### Anorexia

The absence or loss of appetite for food is common in patients with advanced cancer and other chronic illnesses. It is important to look for secondary anorexia which may be reversible. e.g. dyspepsia, altered taste, malodour, nausea, vomiting, constipation, sore mouth, pain, biochemical abnormalities, drugs, radiotherapy, chemotherapy, anxiety and depression

### Cachexia

Cachexia is a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without fat mass) that cannot be fully reversed by conventional nutritional supports and leads to functional impairment. Cachexia is characterized by negative protein and energy balance caused by a variable combination of reduced food intake and abnormal metabolism.

Anorexia-cachexia syndrome is often accompanied by asthenia or fatigue. This is described by the patient as unusual tiredness, decreased capacity for work, decreased motivation, mood and energy, decreased concentration and mental agility.

#### Non-pharmacological management of anorexia

- Small but frequent meals
- Energy-dense food
- Limit fat intake
- Avoid extremes in the smell
- Pleasant environment
- Presentation of food to the patient in a pleasing manner

#### Pharmacological management of Anorexia

Progestones (megestrol acetate and medroxyprogesterone acetate) are the first-line therapy for cancer anorexia. They are effective in relieving the symptoms of cancer anorexia and thus are widely prescribed. In a recent systematic review of randomized clinical trials, Maltoni and co-workers showed that high-dose progesterone (up to 800 mg/day of megestrol acetate and up to 1000 mg/day of medroxyprogesterone acetate) improve food intake and to a lesser extent, body weight and performance status.

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

Prokinetic drugs such as metoclopramide may help in anorexia due to gastric stasis.

Thalidomide, omega-3-fatty acids, melatonin and NSAIDs are also considered as emerging medicines in the management of anorexia-cachexia, but they need more research.

#### Nursing interventions

- Observe and assess for signs of dehydration and/or over-hydration (check for full bladder).
- Regular mouth care.
- Offer regular sips of fluid/ice chips/ice-blocks/electrolyte drinks.
- Review medications, particularly anticholinergics, diuretics, tricyclic anti-depressants.
- Observation of thirst and polyuria that could indicate hypercalcaemia or Diabetes.
- Maintaining a conducive environment such as good ventilation, optimum light, clean bedding
- Ongoing reassurance and education of family members and patient.

#### Considerations

- It has been stated that dehydration is part of the normal process of dying, and could act as an anaesthetic.
- Unwanted fluid can become a burden for the body.

#### Diet explanation

- Ask patients preference / choices of food

- Encourage frequent small feeds ( 6 -7 times)
- Advice frequent mouthwashes with saltwater/ lime water/drinking water
- Homemade foods are encouraged.
- Small quantity with more calories and more protein.
- Never force the patient for food.
- If the patient has nausea – high protein may increase nausea and vomiting
- Salt intake is mandatory unless the patient has any cardiac /renal problems / hypertension.
- Explain to relatives that loss of appetite is expected and the patient should not be forced to eat more than he can willingly take.

## Chapter 8:

# Care of Bedridden Patient

### Learning Objectives

At the end of the session, you should be able to

- 1) Understand the importance of the care of bed-ridden patients and demonstrate the care systematically.
- 2) Identify the problems of bed-ridden patients
- 3) Educate the family about the care of the patient.
- 4) Demonstrate the care to the family.

### Group activity

A 76-year-old man is bedridden following a major stroke. He is unconscious and is on nasogastric feeding and has urine and faecal incontinence.

- 1) Teach family members about the care required
- 2) Suggest interventions to prevent bedsores.

### Introduction

Nursing care of bed-ridden patients is a quite challenging patient may be conscious or unconscious.

The significant problems in a bed-ridden patient (conscious and unconscious) are:

- Corneal ulcer
- Pressure sore
- Malnutrition
- Psychological problems
- Electrolyte imbalance.

In a bed-ridden patient, the care includes:

- Health education of the family.
- Involving the family in the care.
- Demonstrate the care and make a follow-up plan.
- Regular home visits.
- Airway clearance
- Adequate fluid intake (oral, nasogastric tube feeding)
- Bowel and bladder care

- Personal hygiene- head to foot care
- Prevention and care of pressure sores
- Exercise
- Communication
- Assessment of symptoms, recording and reporting

### **Mouth care**

If the patient is conscious, help the patient in his mouth care. If the patient is unconscious, the carers need to be taught mouth care by demonstrating the procedure. Solutions which can be used are - Normal Saline, lime juice, neem leaves boiled in water, toothbrush and toothpaste. Daily assessment is recommended. Brush and rinse mouth twice daily or according to the patient's condition. Soak dentures overnight. Apply lip balm for cracked lips

### **Care of dependent patients:**

- 2 or 4 hourly mouth care (assess individually)
- Use of soft brush, foam sticks applicator or glove and gauze
- Use of syringe for gentle mouth wash
- Avoid lemon and glycerine as it causes dry mouth

### **Assisted oral care**

- Explain the procedure to the patients and help them. Assemble the things needed for mouth care, i.e. toothbrush, toothpaste, small basin, water in a jug, towel, lip lubricant (Needs demonstration)
- Put him on side-lying position with a towel below the cheek. Cut short the bristles of the toothbrush and wrap with the gauze or sterile cotton cloth.
- One tsp of salt in 500ml of water and boil. Remove all the water from the mouth to prevent aspiration.

### **Care of hair and how to give the head bath**

Stimulating the scalp by massage and brushing improves circulation and keeps hair healthy

### **Care of eyes**

The most common problem of the eyes is secretions that dry on the lashes. This may need to be softened and wiped away. Each eye is cleaned from the inner to the outer corner with separate swabs 3 or 4 times daily with boiled, cooled water.

### **Care of nose and ears**

Excessive collection of secretions makes the patient sniff and blow the nose. External crusted secretions can be removed with a wet cloth or a cotton applicator moistened with oil, normal saline or water.



## Bed bath

Bathing is essential in maintaining and promoting hygiene. It helps:

- To clean the dirt from the body
- To increase elimination of wastes through the skin
- To prevent pressure sores
- To stimulate circulation
- To induce sleep
- To provide comfort
- To relieve fatigue.
- To give the patient a sense of well-being
- To regulate body temperature
- To provide active and passive exercises

## Points to remember while giving a bed bath

- Protect the bed linen and pillow cover with a towel and mackintosh
- Place a mackintosh under the patient's head and neck. Keep one end of the mackintosh in a bucket to receive the water. Wash thoroughly with soap or shampoo
- Rinse thoroughly and dry the hair. Braid the hair into two on each side of the head, behind the ears to make the patient more comfortable when lying on her back

## General instructions for bed bath

- Maintain privacy
- Explain the procedure
- Patient's room should be warm and free of draughts
- All needed equipment should be at hand and conveniently placed
- Avoid giving unnecessary exertion to the patient
- Remove the soap completely from the body to avoid the drying effect
- Only a small area of the body should be exposed and bathed at a time
- Support should be given to the joints while lifting the arms and legs during the cleaning and drying of these areas
- Provide active and passive exercises whenever possible unless contraindicated
- Wash the hands and feet by immersing them in a basin of water because it promotes thorough cleaning of the fingernails and toenails
- Cut short the nails, if they are long
- A thorough inspection of the skin, especially at the back of the body should be done to find out the early signs of the pressure sore

- All the skin surfaces should be included in the bathing process with special care in cleaning and drying the creases and folds and the bony prominences, as these parts are most likely to be injured
- Cleaning is done from the cleanest area to the less clean area, e.g. upper parts of the body should be cleaned before the lower legs
- The temperature of the water should be adjusted for the comfort of the patient
- Creams/oils/paraffin is used to prevent drying and excoriation of the skin
- Keep the patient near the edge of the bed to avoid overreaching and straining of the back of the caregiver

### **Backcare**

- Patients, who are prone to pressure sores, must have their back care every 2 hours or more frequently
- Wash the back with soap and water, dried and massaged with any available lubricant to prevent friction
- Massaging helps to increase the blood supply to the area and prevent pressure sore
- Give special attention to the pressure points
- Dry the area by patting and not by rubbing
- Stroke with both hands on the back

### **Nutrition**

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 all the things 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 gives water for hand washing and oral care

Naso-gastric feeding is given to the patient who is not able to take orally. The following points are to be kept in mind:

- Give the patient a fowlers position or raise the chest with extra pillows.
- Prevent entry of air inside the tube by pinching or folding the tube and open the cap, fix the syringe (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 feed give about 50ml of plain water.
- Give a total of 200 ml of prepared feed. (Total feed plus water not to exceed more than 250 ml)
- Give the feed slowly without air entry.
- After feed gives oral care
- Keep the Patient in the same position for half an hour
- Then put the patient on side-lying position (to drain the secretions out of the mouth and prevent aspiration)
- Give two-hourly feed and after 10 pm (night) just two feeds at 3 hours interval.
- Prepare feed at home with what is available like vegetable and daal soups, milk, water, fruit juice, rice cooked water.
- Before giving the feed, strain and then give the food.

### Active and passive exercise

Exercise must be integrated into the patient's daily life as it prevents contractures, foot drop and wrist drop. All the joints need physiotherapy. Educate the family about the importance of exercise to prevent joint stiffness. If there are no restriction or bone problems, exercise can be given by the patient's family.

### Care of perineum

Perineal hygiene involves cleaning the external genitalia and surrounding areas. The perineum is prone to the growth of pathogenic organisms because it is warm, moist and is not well ventilated. Thorough cleaning is essential to prevent bad odour and to promote comfort. The perineum should be cleaned after each act of urination and defecation. Clean with soap and water daily 3 to 4 times and keep the area dry. Clean from the cleanest to the less clean area. The urethral orifice is considered as the cleanest area, and the anal orifice is considered as the least clean area. Hands should be cleaned after giving perineal care.

### Bladder care

Bladder care is important in bed-ridden and catheterised patients.

How to help the patient suffering from incontinence?

- Give privacy
- Provide bedpan, urinal or commode if needed.
- Provide massage for painful areas, if possible.
- Give hot water fomentation on the lower abdomen or a wash with warm water.
- Stimulation by seating Patient next to running water
- Patient should be given enough time to empty the bladder completely
- Urine collection devices

**Diapers absorb urine, facilitates care, allows social integration.**

**Disadvantages:**

- Need to change frequently (2-4 hourly) or else the potential for skin breakdown.
- Expensive and difficult to change.
- Often used in incontinent demented patients with adequate bladder emptying.
- Condom catheters need to change once daily, less bulky, but the chance of penile skin breakdown.
- A slight increase in UTI.

Patient with an indwelling catheter needs:

- Cleaning from the umbilicus to mid-thigh daily once.
- Cleaning the vulval area and catheter 2 or 3 times daily with soap and water.
- Foley's catheter has to be changed every 3 weeks
- Increase intake of fluid to about 2- 3 litres /day
- Urobag should be kept below the waist level
- Keep the urobag cap always closed.
- Empty bag when it is 3/4th full.
- Observe if urine is draining freely
- Secure the urobag below the waist or leg while walking.
- Observe the colour and amount of urine.

**Condom catheter**

Needs to be considered when all other options fail/cannot be applied. Patients are usually provided with two condom catheters. It must be removed, cleaned and changed twice daily. Catheters can be used until they get damaged. Penile ulceration is due to the collection of urine in between the catheter and the penis. To prevent this, place the condom upwards towards the suprapubic region and not around the penis. Skin excoriation and penile ulceration are more evident when the catheter is stuck around the penis allowing the collection of urine around the penis.

**Bowel Care**

Constipation is more common than diarrhoea. Carefully assess bowel function daily. Take a detailed history. Passage of hard stools is difficult and painful. Always compare with the patient's regular bowel habit. Find out whether he/she is regularly taking laxatives. If a record of bowel habits is maintained, it will help in proper bowel management.

### **Prevention is the key.**

If a cause is identified for constipation, remove if possible. Regular exercise reduces the risk of constipation. Encourage deep breathing, abdominal massage etc. Encourage intake of fibre rich diet and fluids.

### **Lifting and moving patients**

It may be very often necessary to lift and move bedridden patients. Unless done in the proper way, this manoeuvre can be damaging both to the patient and carer. It is important to keep some key points in mind while shifting patients. Mechanical devices are available to help with this activity. But very often they are not affordable to many patients at home.

- a. Consider the weight of the patient
- b. Identify the need for help before lifting. Do not attempt to lift the patient by yourself
- c. Get one partner
- d. Communicate with the partner
- e. Have a plan
- f. Use your legs to lift
- g. Have the feet positioned properly
- h. Keep the weight close to the body
- i. Lift without twisting

### **Prevention:**

- Simple measures should be incorporated as part of the routine plan in all patients
- Maintain good symptom control
- Mobility: Activity is the key stimulus to colonic peristalsis and defecation. Mobility should be encouraged as much as possible
- Maintain adequate oral fluid intake
- Use of bedpans: It is mandatory to maintain patients' privacy and use of a commode or lavatory for defecation

## Chapter 9:

# Pharmacology

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### Learning Objective

**At the end of the session, you should be able to**

- 1) Describe the role of Community Health Officer in administering drugs
- 2) Describe strategies to improve drug compliance

Medicine is the science and practice of establishing the diagnosis, prognosis, treatment, and prevention of disease. Medicine encompasses a variety of health care practices evolved to maintain and restore health by the prevention and treatment of illness. Any component that can be used against diseases for diagnosis, prevention, cure, alleviating sufferings, and restoration of health can be categorized as medicine or drug. The branch of science that deals with the study of drugs are known as Pharmacology.

### The role of a Community Health Officer in administering medicine

1. Wash hands before drug administration
2. Follow the 10 Rights:
  - a. Right patient
  - b. Right drug
  - c. Right dose
  - d. Right time
  - e. Right route
  - f. Right documentation
  - g. Right patient education
  - h. Right to refuse
  - i. Right assessment
  - j. Right evaluation
3. Check the expiry date of the medicine
4. Before the administration of a drug, the nurse should know the therapeutic action, uses, side effects, adverse effects of a drug and the precautions Community Health Officer taken while administering the drug
5. Ensure that the drug has not been administered by the family member/others before the arrival of the home-care team

6. Explain to the patient and the family why this medication is being given
7. During home visits, check the medicine wrapper/packing/box to ensure that the right drug is in the right package and to check the compliance and adherence to prescription

While the responsibility of the pharmacist is only to provide the right medicine based on composition and the overall quantity as prescribed by the doctor, it is the Community Health Officer who ensures that the correct method, dosage, and time intervals in administering medicines to a patient are well monitored. Therefore, it is essential that the Community Health Officer are well aware of the medicines.

- a) Name of the drug – Every medicine has two names; the first one is its Chemical name or its Pharmacological Name, and the second one is its trade name or its brand name. The Chemical name or Pharmacological name is unique based on its composition. Whereas, the trade name or brand name is given by the companies and therefore it varies for the same chemical name. For example, Paracetamol is available in Calpol, Crocin, Dolo, P'mol, Febrex. Diclofenac sodium is available as Voveran, Nac, Diclofen, Diclon. Glibenclamide is available as Daonil, Glinil, Gliben, and Dinil
- b) Classification of drugs – The medicines are classified based on their usage, purpose, and its chemical composition. Classification of some of the essential medicines and most commonly used medicines are as follows
  - 1) Analgesics – to alleviate pain, such as Meloxicam, Diclofenac
  - 2) Antipyretics – To lower fever such as Paracetamol
  - 3) Anaesthetics - used during tests and surgical operations to numb the sensation in certain/particular regions in the body or to induce sleep, such as Lignocaine, Sensorcaine
  - 4) Antidotes – a drug administered to counteract poisoning due to excessive administration of another drug such as Naloxone which is used as an antidote against excessive Morphine
  - 5) Anti-inflammatory – to reduce swelling such as Diclofenac, Ibuprofen
  - 6) Anti-Coagulants - to prevent coagulation of blood such as Heparin Sodium, Aspirin, and Clopidogrel
  - 7) Anti-Histamines – to prevent or to reduce allergic reactions such as Pheniramine
  - 8) Antacids – To reduce acidity and gastric symptoms, such as Gelusil MPS
  - 9) Anticonvulsants - antiepileptic drugs(also termed as antiseizure drugs) are a diverse group of pharmacological agents used in the treatment of epileptic seizures, such as Phenytoin sodium, Phenobarbitone
  - 10) Anti-Pruritics – drugs that inhibit the itching and its inflammation, example Calamine lotion, Pheniramine
  - 11) Antibiotics – Antimicrobial medicines active against bacteria such as Amoxicillin, Ciprofloxacin
  - 12) Antitussives – for dry cough, such as Dextromethorphan, Codeine syrup
  - 13) Anti-asthmatics – For Asthma treatment example Deriphyllin, Salbutamol
  - 14) Antiseptics - antimicrobial substances that are applied to living tissue/skin to reduce the possibility of infection, sepsis, or putrefaction such as Hydrogen Peroxide, Dettol, Savlon



- 15) Antifungals – To reduce and to treat fungal infections, example Clotrimazole, Fluconazole
- 16) Anti-spasmodics – For muscle spasms Eg: Dicyclomine
- 17) Anti-emetics – An antiemetic is a drug that is effective against vomiting and nausea. Antiemetics are typically used to treat motion sickness and the side effects of opioid analgesics, general anaesthetics, and chemotherapy directed against cancer. E.g., Metoclopramide, Ondansetron
- 18) Anti-hypertensives / Hypotensives – To regulate blood pressure, e.g., Amlodipine, Nifedipine
- 19) Anti-depressants – used in the Management of Depression – Eg: Amitriptyline, Fluoxetine
- 20) Bronchodilators – a medication that relaxes and opens the airways, or bronchi, in the lungs - Deriphyllin, Salbutamol
- 21) Corticosteroids - a class of drug that lowers inflammation in the body. They also reduce immune system activity. Because corticosteroids ease swelling, itching, redness, and allergic reactions, doctors often prescribe them to help treat diseases like asthma. These are of two types – Glucocorticoids and Mineralocorticoids – e.g., Dexamethasone, Betamethasone/ Hydrocortisone
- 22) Diuretics - any substance that promotes diuresis or increased production of urine. This includes forced diuresis. There are several categories of diuretics. In general, all diuretics increase the excretion of water from bodies, although each class does so in a distinct way. E.g., Frusemide
- 23) Expectorants - a medicine which promotes the secretion and elimination of sputum by the air passages, used to treat cough. E.g., Ambroxol expectorant
- 24) Haemostatics - promotes hemostasis (stops bleeding) – e.g., Ethamsylate, Tranexamic acid
- 25) Emollients – Prevents skin dryness, softens skin, and soothing skin, e.g., Aloe vera, Vaseline, liquid paraffin.
- 26) Haematinics – to increase blood haemoglobin level e.g., Iron, Folic acid
- 27) Hypolipidemics – To reduce cholesterol level, example Atorvastatin, Rosuvastatin,
- 28) Hypoglycaemics – To reduce sugar level in the blood, e.g., Glibenclamide, Insulin, Metformin
- 29) Muscle relaxants - a drug that affects skeletal muscle function and decreases the muscle tone. It may be used to alleviate symptoms such as muscle spasms, pain, and hyperreflexia. E.g., Diazepam, Baclofen
- 30) Opioids (Narcotics) – Pain medication, a psychoactive compound with sleep-inducing properties, and euphoric properties. e.g., Morphine
- 31) Carminatives – To relieve flatulence, example Carminative mixture
- 32) Laxatives – Loosen stools, and increase bowel movement, e.g., Bisacodyl, Cremaffin

c) Types/ Formulations of medicines

Most medicines come in a variety of types of formulations. Be aware, though, that some medicines (particularly rare or unusual ones) only come in one or specific formulation, e.g., Injection Amikacin. Also, some may be more effective in one formulation than another, Eg: Iron formulations (Tablets, Capsule, Injections, Syrups).

## Preparations

- **Liquid:** The active part of the medicine is combined with a liquid to make it easier to take or better absorbed. A liquid may also be called a 'mixture', 'solution' or 'syrup'. Many common liquids are now available without any added colouring or sugar.
- **Tablet:** The active ingredient is combined with another substance and pressed into a round or oval solid shape. There are different types of tablets. Soluble or dispersible tablets can safely be dissolved in water.
- **Capsules:** The active part of the medicine is contained inside a plastic shell that dissolves slowly in the stomach. You can take some capsules apart and mix the contents with your child's favourite food, Eg: Amoxicillin. Others need to be swallowed whole, so the medicine isn't absorbed until the stomach acid breaks down the capsule shell, Eg: Cap. Vitamin E.

## Other formulations of drugs:

- Topical medicines
- Suppositories
- Drops
- Inhalers
- Injections
- Implants or patches
- Tablets you don't swallow (known as buccal or sublingual tablets or liquids)

### d) Effects of the drug

- Therapeutic Effect
- Systemic Effect
- Local Effect
- Side Effect

### e) Dosage

- Minimum Dose
- Maximum Dose
- Over Dose
- Lethal Dose

## The dose of a drug depends on

- Age
- Weight
- Sex

- Physical Condition
- Cumulative action of the drug
- Tolerance
- Habituation
- Addiction
- Co-Morbidities and Drug Interactions

f) Routes of administration

Local Routes: Topical, Deeper Tissues, Arterial supply

Systemic Routes: Oral, Sublingual or Buccal, Inhalation, Nasal, Rectal, Cutaneous, Parenteral (Intravenous IV, Intramuscular IM, Subcutaneous SC, Intradermal ID)

g) Time of administration

A/F	After food
B/F	Before food
a.m., am, AM	morning
b.i.d., bid, bd	twice a day / twice daily / 2 times daily
h.s.	at bedtime
ii	two tablets
iii	three tablets
n.p.o., npo, NPO	nothing by mouth / not by oral administration/ Nil Per Oral
o.d., od, OD	once a day
p.m., pm, PM	afternoon or evening
p.o., po, PO	Per orally / by mouth / oral administration
p.r., pr, PR	per rectally
p.r.n., prn, PRN/SOS	as and when needed, (also Pertactin - a key antigen of ac.Pertussis vaccine)
q.	every
q.1.d., q1d	Once every day
q.1.h., q1h	every hour
q.2.h., q2h	every 2 hours
q.4.h., q4h	every 4 hours
q.6.h., q6h	every 6 hours
q.8.h., q8h	every 8 hours
q.d.s, qds, QDS	4 times a day
q.i.d, qid	4 times a day
q.o.d., qod	every other day/alternate days
Rx, Rx, R	prescription
Stat.	immediately, with no delay, now
t.d.s, tds, TDS	3 times a day

## **h) Indications**

### **Abbreviations**

- Inj.- Injection
- Tr. -Tincture
- Syp. -Syrup
- Liq.- Liquid
- Amp- Ampoule
- CR -Controlled Release
- Cap -Capsule
- Tab -Tablet
- Oint- Ointment
- S/L- Sublingual
- SR- Sustained release
- Sus -Suspension
- DS -Double strength
- HS-Half Strength
- DT- Dispersible tablet
- EC- Enteric-coated
- ER- Extended-Release
- FC- Film Coated
- Inf-Infusion

### **Storage of Medicines**

Standard practices must be followed to ensure safety and shelf life while storing medicines. The storeroom for medicines must be a separate room or a cupboard in an isolated area with provisions to keep the storage locked for authorized access. The site identified for medical storage must be tested to ensure low humidity, ensuring the surfaces and surroundings are free from moisture. The site must also be protected from direct sunlight. The following guidelines may be followed while storing medicines

1. Medicines must be labelled and placed in its designated locations
2. Crosscheck that all essential medicines are available against a master checklist
3. The medicines rack is categorized in alphabetical order of the name of the medicines
4. Tablets and Capsules must be placed in separate containers
5. Tablets, Capsules, Syrups, Powders should be arranged separately
6. Medicines for internal intake and external use must be stored in separate levels of racks

7. Labels placed on container tops should not be misplaced on other containers. Provisions may be provided for avoiding human errors
8. If a change in colour, shape or smell is noticed in medicines, then it must not be distributed
9. The required storage temperature for medicine must be marked on the labels. Ensure to follow the storage instructions while placing the medicines
10. Emergency medicines should be stored by ensuring visibility and quick access
11. While distributing medicines or administering to patients, Community Health Officer should explain the purpose of the medicine, dosage, and medicine intake timings to the patients then mark the same on the medicine covers
12. Recheck that the medicine being distributed matches with the prescription
13. Maintain a register of medicines distributed to patients
14. The storeroom of medicines must always be maintained locked with limited access for authorized people. The responsibility of the medicine storeroom should be assigned to the senior nurses.
15. The stock register of medicines should contain invoice number, date, from who received, to who issued, received quantity, batch number, maximum retail price or MRP, issued quantity, balance quantity, name of the manufacturer, rate per strip, and expiry date

### **Safety measures while handling medicines**

The following directions should be followed while handling medicines

1. Cross verify the following are matching before administering medicines
  - a) The right medicine
  - b) The right patient
  - c) The right time
  - d) The right dosage
  - e) The right route
  - f) The right documentation
2. Medicines must be administered or distributed strictly as per an authorized doctor prescription. In case of any doubt on the prescription, get it clarified from the relevant authority before administering to the patient.
3. Medicines may be administered as per oral instruction in emergency situations. In such situations, a doctor's prescription must be collected at the earliest possible.
4. If a change in colour or smell of the medicines is observed, it should not be distributed

5. Community Health Officer must be educated about the minimum dosage and maximum dosage of each medicine that they handle. And the medicine should be distributed at the right intervals.
6. In case of an error in administering or distributing medicine happens, the authorized doctor must immediately be informed about the same.
7. A record about medicine should be entered in the registry only after administering the medicine. The registry must contain the name of the medicine and the time of administering it.

### **Ethical and Legal Aspects of Medicine**

- The right to prescribe medicines is limited only within the doctors authorized by the Indian Medical Association.
- While a Community Health Officer can administer any medicine prescribed by the doctor, the doctor who prescribed it is responsible for all its effects.
- Medicines must be distributed strictly based on the instructions in a prescription from an authorized doctor. As an exception, if a medicine is administered as per oral instructions during an emergency, the same must be collected as a written prescription by the Community Health Officer at the earliest after attending to the emergency
- All the possible side effects of a medicine should be explained to the patient it is being administered to.
- The patient has the right to reject any treatment that he is not interested in.
- Certain medicines such as Morphine should be prescribed only by authorized doctors with respective licenses to do so.
- The medicines that passed expiry must be destroyed during disposal.
- If the medicine that is being administered is under clinical trial, then an authorization letter with signed approval by the patient must be collected in advance in prior. In such an event, the patient must be educated about the medicine with information that the medicine is under trial, and the effects of it on the human body are not completely known.
- The documented records on the details of medicines administered to must be provided to the patient, with a copy retained at the clinic for a minimum of three years.

### **Medicines and Compliance**

Treatment of disease will be effective only if the patient takes the medicines strictly as per prescription. Making the patient fully aware of the importance of adhering to prescribed medicines is an essential part of treatment. Nurses have a crucial role to play in enlightening the patient about what the medicines are, their specific role nurse write Community Health Officer side effects, if any, besides ensuring that the patient takes them regularly.

### **Why do patients not take medicines regularly?**

- Lack of awareness about the action of the medicines
- Inability to understand the information and instructions given by the physician or the pharmacist
- Dislike the taste of medicine
- Fear of addiction to medicine

- Problems associated with side effects
- Having to take multiple medicines at the same time
- Having to take medicine too frequently
- Prolonged treatment
- The duration of waiting in hospitals
- The cost of medicines

Excessive use of medicines is undoubtedly dangerous. However, not taking the required amount of medicine will lead to treatment failure. It must be emphasized that consuming medications prescribed for someone else is dangerous, even if the symptoms appear to be identical.

### **How to convince the patient to adhere to medicines?**

- Discuss the need and importance of each medicine
- Discuss when to take medicine (before or after food), and the correct dosage. Discuss the way each medication must be taken (tablets or capsules that should not be powdered or broken)
- Discuss the way medicines are to be given to patients who are being fed through a tube
- Discuss the way suppositories are to be inserted into the rectum
- Discuss how medicines are to be kept under the tongue
- Discuss the course of action if a dose of the medicine was accidentally not consumed
- Discuss the side effects, if any, of medicines
- Discuss how to keep the medicines safely

### **How to ensure the patient takes his medicines?**

- Visit the patient at his home and enquire about details of medicine with the patient or the caregivers.
- The query for details about the timing and quantity of each medicine being taken.
- Compare the packaging and the drug chart.
- Find out when and what quantity of medicines were bought and how much was remaining.
- Find out the problems associated with consuming medicines.

### **Common mistakes**

- Mixing up of medicine packets after they are picked for consumption.
- Mixing up and repeatedly taking one particular medicine instead of different medicines.
- Mixing up of medicines of similar shape and colour.
- More than one person helping with administering medicines (leading to an overdose of medicine).
- Mixing up of medicines with different potency.

Ayurveda proposes guidelines and detailed methodology of healthy living and treatment of various medical conditions which are time tested and applicable to current healthcare issues. Internally ill cancer patients, poor prognosis, unfruitful efforts, lost hope from relatives and patient may dilute



intent of treatment resulting in worsening the condition medically, mentally, morally and socially. However, it's ethical, moral responsibility of healthcare professional to make every possible effort for betterment and convenience of the patient. Through this narrative review, here we try to explore the scope of Ayurveda interventions in improving palliative care practices of terminally ill cancer patients. Ayurveda can play a major role in palliative care through some suitable, convenient treatment measures along with conventional palliative care. Ayurveda interventions viz. Vrana karma (wound care), Basti (per rectal drug administration), Snehan-svedan (massage, fomentation), Kawal-gandoosha (gargling), Shiro-snehan (oleation of head), etc. may contribute as alternative or complementary to ongoing palliative care practices of wound care, urine-bowel related issues, ambulation, oral hygiene, stress management, and pain management respectively. Various yaapana basti to nourish body and Nasya (Nasal instillation of medicine), Kar- improve quality of life (QoL) in cancer patients can be used. Ayurveda offers pain management through appropriate use of the above measures by reducing pain intensity, frequency, and dependence on pain killers. Conventional palliative measures can be supported by these measures of Ayurveda principles and practices for better convenience of patients without supplanting current practices. Ayurveda proposes guidelines and detailed methodology of healthy living and treatment of various medical conditions which are time tested and applicable to current healthcare issues. In terminally ill cancer patients, poor prognosis, unfruitful efforts, lost hope from relatives and patient may dilute intent of treatment resulting in worsening the condition medically, mentally, morally and socially. However, it's ethical, moral responsibility of healthcare professional to make every possible effort for betterment and convenience of the patient. Through this narrative review, here we try to explore the scope of Ayurveda interventions in improving palliative care practices of terminally ill cancer patients



## Chapter 10:

# Nursing in Palliative Care

### Learning Objective

At the end of the session, you should be able to

- 1) Describe essential steps in caring for a patient with a bedsore
- 2) Educate family members about prevention and nursing management of wounds
- 3) Describe essential steps in caring for a patient with fistula
- 4) Describe essential steps in caring for a patient with ostomies
- 5) Educate family members about prevention and nursing management of ostomies
- 6) Describe essential steps in caring for a patient with lymphedema

### Group activity

1. A 36-year-old lady with infiltrating duct carcinoma breast reports with local recurrence. The fungating ulcer smells bad and is painful.

### What will you suggest?

2. A 45 yr old lady with oral cancer after radio/chemo with fistula moderate to severe pain and headache unable to sleep in the night.

### How will you manage?

### PRESSURE SORES

A pressure sore or pressure ulcer is an injury to the skin and tissue underneath, usually caused by unrelieved pressure. Pressure on a small area of the body can compress tiny blood vessels that generally supply the tissue with oxygen and nutrients resulting in insufficient blood flow and necrosis of the area.

### Purpose of care

With proper treatment, most pressure sores will heal. Healing depends on many things, general health and diet, relieving pressure on the sore and careful cleaning and dressing.

Stages of Pressure sore:

- 1) The characteristic feature of the Stage 1 pressure sore is Non-blanching redness. But this feature may not be very obvious in people with darker complexion but the area looks and feels characteristically

distinct from the surrounding areas. The site is usually painful, may feel warm or cold compared to the surrounding area.

- 2) In stage 2 pressure ulcer, there is a partial loss of dermis. There is an open ulcer. The wound bed appears as pink and red with serosanguinous exudates. There may also be blisters filled with serosanguinous fluid that are yet to rupture. The sloughs or eschar are absent in stage 2 pressure ulcers.
- 3) Stage 3 pressure sore is characterised by full-thickness skin loss. The ulcer exposes the subcutaneous fat or extends into the subcutaneous fat but not the muscles, tendons or bones. There may be undermining or tunnelling in stage 3, so one has to carefully examine stage 3 ulcers. The stage 3 pressure sore may quickly progress into stage 4 in those who have very thin built as they have less subcutaneous padding. Similarly, the areas with less subcutaneous fat such as occiput, ear, scapula, sacrum, heel and malleolus the progression from stage 2 to stage 4 will be rapid.
- 4) Stage 4 pressure sore is characterised by loss of full thickness of the skin with the ulcer extending into muscles, tendons and bones like a deep crater. The depth of the ulcer will vary based on the location of the ulcer. Similar to stage 3, there may be undermining or tunnelling. The presence of slough or eschar is common. A stage 4 pressure sore may lead to osteomyelitis that can further complicate the management.

Unstageable pressure sore: To stage a pressure sore, one needs to visualise the base of the wound. When the base of the wound is covered by slough or eschar then the pressure sore is called unstageable pressure sore. Once the slough is removed, the pressure sore is usually stage 3 or stage 4. In an unstageable pressure sore, there is a loss of full thickness of the skin.

#### Assessment of a patient with a wound:

Co-morbidities and personal habits that can complicate the wound management	Diabetes, Peripheral vascular disease, Coronary artery disease, Substance abuse, Tobacco use
Impact of the wound on the day to day activities of the patient and the family	Ability to perform Activities of daily living Ability to go for work
Patients' self-care ability	Can the patient perform dressing on his own?
Primary caregivers' ability	Can the primary caregiver follow through the advice given? His/her problems and concerns.
Patients' nutritional status	General built Consumption of a balanced diet including, rice, grams, pulses, meat and green leafy vegetables.
Social support structure	Are there volunteers to help the family? Is anyone available for dressing the wound daily?
Sleep and rest	Is the patient able to sleep well? How many hours of sleep per day? Is there any difficulty in resting?

## Management of Pressure Sore

### 1. Prevent pressure sore development

- Daily examination of pressure points and skin
- Daily bath
- Keep skin soft and moist
- Prevent incontinence of bowel and bladder
- Encourage ambulation and exercise
- Identify patients prone to develop pressure ulcers
- Change the position of the patient every two hours (in lying down position) and every hour (in sitting position)
- Keep the Patient's skin well lubricated to prevent cracking of the skin
- Provide the Patient with adequate fluids and diet that is with high protein content and vitamins
- Encourage a balanced diet to keep tissues healthy
- Attend to the pressure points at least two hourly to stimulate circulation
- While giving and taking bedpans, lift the patients and then only remove the bedpan to avoid the friction
- Provide a wrinkle-free bed
- Use special mattresses like air or water mattresses. Avoid poorly ventilated mattress
- Cut fingernails short
- Encourage the Patient to move in the bed as far as possible
- Change the linen when wet
- Educate the family members about the hygiene care of the skin and pressure sore prevention

### 2. Relieve the pressure

- Reposition every 2 hours
- Do not rest on hip bone directly.
- Avoid elevation of the head end of the bed
- Use special devices to relieve pressure such as air cushions, waterbed, foam pads or pillows

### 3. Pressure sore care

- Use normal saline for cleaning and irrigating the wound
- Remove dead tissues and scab

- Use moist dressing material; this prevents damaging granulation tissue while changing the dressing.

#### 4. Points to remember

- Maintain daily hygiene with a sponge bath, shower, hair care, and shave, trim nails
- Maintain hygienic environment, such as clean clothing, and bed linen
- Assess skin integrity, especially pressure points, in areas such as sacrum, hips, heels, ankles, ribs, vertebrae, spine, shoulders, elbows, and ears
- Patient with poor mobility needs a change of position every 2-4 hours
- Positioning of pillows
- Massage (attention must be paid to avoid since massage can cause tissue damage at pressure points)
- Pad bony prominences for protection,
- Use waterbed or air mattress
- Awareness of friction and shearing forces
- Education of the family about care procedures

#### Malignant wound care

Cancer wounds can look like a cauliflower growth in some parts and breaking down in others. These wounds may develop during the last few months of life and are very distressing for patients.

#### Assessment of the wound:

Aetiology of the wound	Malignant or Non-malignant ulcer
Nature of the ulcer	Healing, Delayed healing, Non-healing
Dimensions of the wound	Size, shape, depth of the wound and undermining of the wound edges
Exudate	Serous, Sanguineous, Serosanguineous and Purulent.
Malodour	SNIFFF (Smell-Nil, Faint, Foul, Forbidding)
Type of tissue	Granulation tissue, slough, Eschar or Necrotic tissue
The skin surrounding the ulcer	Pruritis, discolouration and dryness
Pain	The severity of pain Type of pain
Maggots	Are there maggots in the wound? Is the wound kept open?
Bleeding	Have there been episodes of bleeding from the wound in the past? Does the wound bleed while performing dressing?
Risk of contamination	Is there a chance of faecal contamination or soiling with urine?

#### Management

- Minimise pain, infection, bleeding, odour and psychological trauma
- Prevent maggots
- Simple dressing material which can be sterilised in a 'pressure cooker' at home is useful

- Dressing should be comfortable, acceptable, cheap and available locally
- The simplest products may be the best and the most cost-effective

### Physical problems

- Location of the wound
- Bleeding
- Infection
- Bad smell
- Pain when changing the dressing

### Psychosocial problems:

Body image issues, denial, depression, embarrassment, fear, guilt, loss of self-respect and social isolation

#### 1. Management of bad smell

- Bad smell is probably the most distressing symptom for the patient's family and caregivers, as it continuously presents and can cause nausea and vomiting
- Can cause social isolation and affect intimate relationships
- Antibiotics destroy the bacteria responsible for malodour. Through bathing will wash out exudates and decrease malodour. The drug most commonly used is Metronidazole. This powder is usually applied once daily but may need to be repeated more often.

#### 2. Management of discharge

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

#### 3. Pain management:

- Deep pain aching /stabbing /continuous pain - Adjust systemic analgesics. Give an extra dose of pain medication half an hour before dressing
- To minimise pain during dressing, previous dressing materials should be soaked and removed. Another method is the use of non-sticky dressings.
- Maintaining the wound in a moist environment will not only reduce dressing adherence but will also protect exposed nerve endings. Pain can be kept in check by using a dressing material that requires less frequent changes.
- Irrigation of the wound with saline rather than cleaning with a gauze swab will reduce pain.
- Complementary therapies can play an important part in pain management; such as relaxation, distraction or visualisation.

#### 4. Management of bleeding:

- Wound bleeding is common in cancer wounds

- Always mask the bleeding with dark coloured 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, and cleaning by irrigation rather than swabbing, will reduce trauma and bleeding.
- Gentle removal of dressing after soaking with saline or water is a good practice.

#### 5. Management of Maggots

- If maggots are present, apply or flush plain turpentine into the wound with a syringe.
- Wait for 10 minutes. Remove maggots with the help of forceps
- Repeat the dressing with turpentine for about 3 to 4 days to remove all maggots
- Always keep the wound to prevent maggots.

#### 6. Management of 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.

#### 7. Patient's comfort

- Use dressings that will be most comfortable to the patient and cost-effective.
- Used cotton saris or any soft cloth can be made into gauze pieces and gamgee pads.
- Coloured pads have the advantage of masking the colour of blood or exudates from wounds.
- Pile up this dressing materials in an idli vessel or a wide mouth open vessel and boil for 20 minutes.
- Preserve these sterile dressings' materials in a clean container.
- Repeat sterilisation every third day.
- Preparation of saline- in 500ml of water add one tsp of salt and boil for 10 minutes.
- Preparation of Vaseline gauze: Gauze can be cut into the desired size, smeared with vaseline, piled up and sterilise in a pressure cooker. The vaseline melts and coats the pieces uniformly.
- Papaya as dressing material: Raw papaya can be cut into thin slices and placed directly on wounds when the surface is even before bandaging. If the wound surface is uneven, the central part of the raw papaya can be made into a pulp and applied as a paste on the wound. This is found to be very useful in promoting the healing of bedsores.
- Controlling malodour from wounds: Ayurvedic preparation: 2-3 drops of ginger grass oil, having a pleasant and soothing odour, is added to half a litre of water and smeared around the wound (not directly on the wound) to mask the foul odour.
- Few drops of ginger grass oil can be added to the water used for mopping the floors
- To control the malodour for bed-ridden Patient with Recto-vaginal fistula (RVF), the following measure can be tried. Place several sheets of newspaper under the bed sheet below the waist of the patient. The carbon in the newspaper is said to absorb the malodour.

## FISTULAS

Is an abnormal passage or opening between two or more hollow viscera or viscera to the external surface.

### Goals of Management

- Containment of effluent
- Management of odour and protection of surrounding skin and tissues.

### Risk factors in the development of fistula

- Obstruction from the malignancy
- Radiation therapy that damages the vasculature and underlying structures
- Post-surgical adhesion
- Inflammatory bowel disease (Crohn's Disease)
- Small bowel obstruction

### Types

- Vesicovaginal - vagina to the bladder
- Recto-vaginal - vagina to rectum
- Urethro-vaginal - vagina to urethra
- Oral fistula

### Assessment

- Assessment of source, condition of surrounding skin, fluid output and electrolyte status.
- Assess odour, colour and consistency of the effluent

### Treatment

- Possible surgery - colostomy for recto-vaginal fistula.

### Management

- Regular cleaning (saline douches)
- Regular change of pads/cloth
- Assessment for mal-odour (metronidazole)
- Antifungal pessaries if thrush develops
- Barrier creams
- Bowel regulation
- Assessment for excoriation of vaginal tissue
- Psychosocial support (could affect relationships and self-esteem of the patient)

- Suprapubic catheter for vesicovaginal fistula
- Sitz bath
- Providing education, such as for women who may decrease their fluid intake in an attempt to alleviate symptoms, which may lead to infection.
- Regular drainage of collecting bag before it gets to 3/4th of its capacity.

Note: women usually do not seek treatment until symptoms are severe thus requiring prompt attention

## 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.

### Parts of a tracheostomy tube

- Outer tube  
The outer tube held in place by a ribbon or tie which is passed through the loops on either side of the opening of the tube.
- Inner tube  
Fits inside the outer tube. The inner tube is held in place by a small flip lock which is located on the top part of the outer tube

### Complications:

- Accidental expulsion of the tube during coughing
- Infection of the wound and lower respiratory tract
- Choking of the Patient due to dropping of food or water into the tracheostomy opening

### 1. Routine care

- Cleaning inner tube - thorough cleaning of the inner tube should be done with soap and water
- The inner tube to 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 him/herself using a mirror.
- Oral hygiene to be maintained
- Prevent entry of insects into tracheostomy tube.
- Prevent the entry of water directly into the stoma while bathing, swimming, and shaving



## 2. Skin care

- Clean the skin around the tracheostomy site with gauze soaked in saline. Protect the skin with a gauze pad, which is cut in the middle so that it can be placed in between the outer tube and skin.

## 3. 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

## 4. Humidification of air

- Place wet sterile gauze (soaked in tap water) on the tracheostomy tube. This helps in humidifying the inhaled air and filters the dust

## 5. Changing the tie

- Tie is used to fix the tube in position. It should be changed by trained persons when dirty.

## 6. Speech therapy and communication

- The Patient is advised to take a deep breath, then close the stoma with finger and then speak. They may be provided with calling bell or paper and pen for communication.

## STOMACARE

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. Whereas, 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

A colostomy involves creating an opening in the abdomen and pulling through a portion of the colon. This allows stool to pass directly from colon bypassing the diseased or damaged part. The consistency and frequency of the discharge from the stoma depend on the type of colostomy performed. There are different types of colostomy, depending on the site

## Stoma management

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

1. Assessment of patients general condition, application of knowledge of the different types of the stoma in planning and evaluating the outcome
2. Management of the stoma and stomal appliances
3. Providing physical and psychological care

**The four main contexts in which patients require stoma care are as follows:**

- they are undergoing stoma surgery as a palliative strategy
- they have an established stoma whose action and management are now being affected by other palliative interventions
- they are in a terminal condition
- they have a fistula or a nephrostomy

**Issues**

- Stoma colour- Normal colour is deep pink to deep red and should be checked regularly.
- 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.
- Stoma necrosis- A stoma with a dusky appearance should be reported to the doctor immediately.
- Stoma oedema- in the early period is normal. So no intervention needed.
- Stoma herniation-. When the patient lies in the supine position, it usually reduces. But in some cases, the hernia does not reduce, and this should be reported immediately.
- Stoma prolapse- occurs because of the weakened abdominal wall caused by abdominal distension and needs surgical intervention. A prolapse of 1.5 cm of stoma outside the skin level is acceptable in case of colostomy, and 3.5 cm of stoma outside the skin level is acceptable in an ileostomy. A prolapse of 5 cm needs surgical intervention.
- Stoma retraction of the stoma- 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:**

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

**Types of Pouches:**

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

A colostomy pouch (or bag) is worn on the outside the body to collect faeces. Proper care of the stoma includes learning how to empty and replace the pouch and watching for skin irritation. If caring for an infant or child with an ostomy, the same information and procedures generally apply. However, the ostomy pouch will be smaller and will need to be replaced every 2 to 3 days. Different adhesives may be used to attach the pouch because a child's skin is more sensitive than an adult's skin. Irrigation is not appropriate for children.

## Irrigating a colostomy

Colostomy irrigation is a way to regulate bowel movements by emptying the colon at a scheduled time. The process involves infusing water into the colon through the stoma. This stimulates the colon to empty

Irrigating a colostomy allows more control over the elimination of waste because it stimulates the intestine to function at a regular time. It is generally done at the same time every day (more predictable outcome) or every other day. If you irrigate, you may need only a cover or pad over your stoma and may not need an ostomy pouch. Irrigation is not practised in children. Irrigation is done for colostomy, not for an ileostomy.

To irrigate a colostomy, you need to have all of the following equipment and supplies ready, including:

- lubricant.
- an irrigation set, which includes a container for water, tubing with a cone end (one end of the tubing attaches to the container and the cone end is inserted into the stoma), and a clamp.
- an irrigating sleeve and belt. (The sleeve is a long and transparent plastic bag which is open at the top and bottom. The bottom portion is usually kept clamped)
- provision for disposing of the waste

### The basic procedure is as follows.

- Getting ready
  1. Place 1 to 1.5 litres of lukewarm water as an irrigation solution (cold water can cause cramps) in the container.
  2. Hang the container at about shoulder height (18inches to 24inches above your stoma) by using a hook or other devices
  3. Find a comfortable position, such as in a chair close to the toilet or on the toilet
- Preparing the equipment
  1. Remove the colostomy pouch from the barrier and snap the irrigation sleeve to it. Attach the sleeve belt for security and place the end of the sleeve in the toilet, bedpan, or another disposal unit.
  2. Unclamp the tubing to let some of the irrigation solution flow through the tubing and cone. This removes air from the tubing.
  3. Clamp the tube
  4. Lubricate the irrigating cone and insert the cone gently into the stoma through the upper opening in the sleeve. Press the cone firmly but gently. Do not force the cone into the stoma or insert it more than 3m into the stoma
- Irrigating
  1. Unclamp the tube and allow the irrigation solution to flow into the stoma slowly for 5 to 10 minutes. If cramps occur, stop the flow for a few seconds, but leave the cone in place.

2. When the desired amount of solution flows in, or when you feel full, clamp the tubing and remove the irrigation cone from the stoma. Waste will come out of the stoma and empty through the sleeve into the toilet or other disposal unit.
3. It takes 30 to 45 minutes for all the waste to get emptied. However, after the initial flow of waste slows down (10 to 15 minutes), you may clamp the sleeve at the bottom and move around.
4. When the waste return gets completed, unsnap the sleeve and put on your usual pouch or covering.
5. Clean all supplies and store for reuse.

By repeating this process regularly, once a day, the colon gets trained to empty with no spillage of waste in between. Colostomy irrigation is a personal decision.

- Who can be a candidate for colostomy irrigation?

Patients with permanent colostomies and whose opening is in the descending or sigmoid colon are good candidates for irrigation. This is because their stools tend to be more formed. People with irritable bowel syndrome, stomal problems, or stomas in the ascending or transverse colons are less likely to have success with irrigation and are therefore not good candidates for colostomy irrigation.

- When is irrigation done?

Colostomy irrigation is most effective when it is done about one hour after a meal when the colon is most likely to be full. Irrigation maybe is done once a day (has a more predictable outcome) or once every other day depending on your preference and ability to regulate your bowel movements. It generally takes about 6-8 weeks for the bowel to become regulated with irrigation. It is important to establish a routine and irrigate at the same time each day.

## Nursing Care

### Bowel Management

It is important to establish regular bowel movements after a colostomy. Habit formation can be established by daily irrigation at a fixed time for 21 days. It may have to be continued throughout life. Every irrigation is usually done with about 1 to 1.5 litres tap water. Irrigation set for the procedure is available. Irrigation can be started after 3 weeks to 3 months of surgery or RT/CT

- Constipation: Laxatives, enema, suppositories.
- Diarrhoea: Increase intake of fluid and provide hospitalisation as early as possible.
- Skincare
  - Daily cleaning with soap and water
  - Dry with a soft towel (mopping)
  - 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
- Use the right size bag
- Malodour could be prevented by adding charcoal to the colostomy bag
- Education
- Diet for patients with colostomy:

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

- Cabbage, garlic, beans and fried food may cause odour
- Corn, Nuts, cabbage and vegetable peeling may cause hardening of stool
- Coffee, Fruits and fruit juices and oily food may cause loose stools
- Mint, Coriander reduces the smell
- Games: Avoid rough games to prevent stoma injury
- Travel: Protect stoma with a bag or a book. Keep extra colostomy bag while travelling
- Sexual life:
  - Counselling for the spouse.
  - Support and encouragement.
  - Avoid pressure being applied on the stoma.

## CARE OF LYMPHEDEMA

Lymphedema is the accumulation of fluid under the skin. It can be due to obstruction or damage to the lymphatic system and resulting blockage 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 the process of diffusion, resulting in lymph stasis. It may be of following types:

Primary – Congenital: Abnormality within the lymphatic system

Secondary -

1. Treatment-related - damage to the lymphatic vessels and nodes by radiotherapy or surgery.
2. Disease-related such as
  - Malignancy - obstruction of lymph flow due to cancer.
  - Trauma - to lymphatic system due to injury
  - Infection- Filariasis.

### Signs and symptoms

- Swelling- Usually unilateral unless the disease trauma is extensive.
- Slow onset, non-pitting oedema
- Skin changes - dry thickened skin, deep creases. Appearance (looks like orange skin), inability to pinch a fold of skin at the base of the second digit.
- Lymphorrhoea
- Joint stiffness and muscle strain
- Discomfort, heaviness and pain

### 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

### Four cornerstones of management

- Skin care: to keep the skin in good condition and reduce the chances of infection.
- Compression bandage/ Hosiery
- Massages
- Exercises

#### 1. Skincare:

- Keep the skin clean and moist.
- Wash skin with mild soap -exceptional attention to folds, between digits & joints
- Use oil or moisturisers. (Avoid perfumed creams)
- Protect from direct heat and sunlight
- Pat dry with a soft clean towel
- Keep area dry & cool
- Avoid tight clothing & jewellery, injections, application of BP cuff on the affected limb, injury to the skin, e.g., burns, sharp instruments, mosquito bite, lifting heavyweights.

#### 2. Compression (bandaging/hosiery) Bandaging - Principles

- Application of graduated compression garments to reduce the volume and improve shape.

- Reshape limb with the bandage in a cylindrical manner
- Apply for 24 hours.
- Low resting pressure rises during exercise.

<b>Bandaging</b>	<b>Hosiery</b>
<u>Indications</u> <ul style="list-style-type: none"> <li>• Fragile or damaged skin</li> <li>• Limb too large to fit hosiery</li> <li>• Distorted limb shape</li> <li>• Pain in the site of lymphoedema</li> </ul>	<u>Indications</u> <ul style="list-style-type: none"> <li>• Intact skin</li> <li>• Patient able to wear and remove it</li> <li>• Limb size and shape allow fitting</li> </ul>
<u>Contraindications</u> <ul style="list-style-type: none"> <li>• Ratio of posterior tibial or brachial artery pressures &lt;0.8</li> <li>• Ventricular failure</li> <li>• Recent peripheral vein thrombosis</li> </ul> <u>Caution with</u> <ul style="list-style-type: none"> <li>• Microcirculatory problems</li> <li>• Absence of sensation</li> </ul>	<u>Contraindications and cautions</u> <ul style="list-style-type: none"> <li>• As for bandaging</li> </ul>

## Exercise

### Aims

- To use a muscle pump.
- To encourage normal activity such as walking.
- To prevent stiffness.

### General Principles

- An important role in fluid drainage.
- Gentle and regular (2 to 3 times daily).
- Wearing compression garments (sleeve and bandage).
- May be done passively

### 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 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 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-clockwise movements at wrist joint (20 repetitions each). Stretch fingers out. Raise arm bending at the elbow. When the 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)

## Massage

### Simple Lymphatic Massage (SLD)

#### Aims

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

#### Techniques

- While massaging, always clear non-swollen side first to clear the way ahead.
- Use dry hands while performing the massage. Cream or powder should not be applied.
- The patient should ideally wear a compression garment during the massage.
- For head and neck swelling, work with nodes at the back and front of the neck, under the chin, occipital nodes, cheeks and lips.

### Massage for Swollen Arm

- Lightly clasp hands-on upper abdomen just below the ribcage.
- Inhale deeply through the nose.
- At the height of breath press abdomen inwards with clasped hands and breathe out slowly (10 repetitions)
- With the flat part of the fingers, move skin just below the ears downwards. While massaging keep the skin stretched (10 repetitions).
- Similar movements at one or two points further down the neck (10 repetitions).
- Gentle scooping movement with two fingertips behind the collarbone. Work from outside towards midline (10 repetitions).
- Upward movement of skin under the armpit of the non-swollen arm (10 repetitions).
- Place the palm on chest next to armpit on non- swollen side. Lightly stretch skin towards the unaffected side. Keeping contact with skin release pressure and allow the skin to return to the original position (10 repetitions).
- Continue these strokes. Stretch skin towards the unaffected side and gradually move to the swollen side.
- When you reach armpit of swollen side stop, repeat breathing exercise (10 repetitions).

### Treatment of Oedema in Advanced Disease

- Daily application of moisturizer



- Treat cellulitis promptly with an antibiotic.
- Treat lymphorrhoea with local antiseptic and absorbent dressing.
- Apply compression bandage for 24 hours.
- When the patient takes rest, elevate and support the limb on a pillow or a raised surface.
- Gentle and light repetitive exercises help to stimulate drainage
- A paralyzed limb needs to be supported in a sling.
- Massage (SLD) will help to soften fibrosis, stimulate lymphatics and improve lymph drainage.
- Compression using garments or bandages will give counter pressure on swelling and improve comfort.

## Chapter 11:

# Common Nursing Procedures in Palliative Care

### Learning Objective

At the end of the session, you should be able to

- 1) Describe the essential steps in caring for a patient on nasogastric tube feeding
- 2) Describe the essential steps in caring for a patient on the urinary catheter
- 3) Demonstrate the procedure: Subcutaneous Infusions

### Naso-gastric Feeding

**Naso gastric Tube:** A nasogastric tube is a plastic tube passed through the nose into the stomach and left in place. A piece of sticking plaster is usually used to keep the tube attached to the nose. It may be in place for a short time or even for many weeks. It is mainly used to pass food, fluids and drugs directly to the stomach when there is difficulty eating by mouth. It needs to be kept clean and free of blockage.

### How to use and care for a nasogastric tube

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 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.
- If the tube has come out of the stomach or is completely blocked, you will need to seek advice from your doctor.

### **Subcutaneous Injection/ Infusions**

Subcutaneous injection is given in the fatty layer of tissue under the skin. 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.

#### **Indications for using this route:**

- Persistent, Nausea and Vomiting
- Dysphagia
- Intestinal obstruction
- Coma

- Poor absorption of oral drugs
- Terminal care

### **Symptoms that can be managed through subcutaneous drug administration**

- o Pain.
- o Nausea and Vomiting
- o Confusion
- o Agitation
- o Respiratory secretions
- o Dyspnoea
- o Seizures

### **Butterfly needle placement for subcutaneous injections and infusions:**

Butterfly needles (Scalp vein) are used for intermittent subcutaneous medication administration and continuous subcutaneous infusions (CSCI). They can be placed and managed at home- care setup. Since they are relatively safe and simple to use, the subcutaneous needles can be placed in homecare set up, and the family caregiver can be taught in administering subcutaneous injections.

### **How to select an appropriate site for subcutaneous infusion:**

- The site should have good depth of subcutaneous fat
- The sites that are easily accessed such as the chest and abdomen are more ideal
- Avoid bony prominence and sites close to the joints
- Rotate the site regularly
- A subcutaneous needle can be in place for a maximum period of 7 days

### **Contraindicated sites for subcutaneous infusion:**

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

### Drugs that can be used

- Inj. Metoclopramide
- Inj. Haloperidol
- Inj. Midazolam
- Inj. Dexamethasone
- Inj. Morphine
- Inj. Fentanyl
- Inj. Rantac

### Advantages

Increased comfort for the patient because there is less need for repeated injection. Control of multiple symptoms with the delivery of drugs in sequential or combination. Compatible drugs can be loaded in the same syringe. Independence and mobility maintained. Round the clock administration of drug provides comfort because plasma drug concentrations are maintained without peak and troughs. Less frequent change of needle site

### Common sites

1. Anterior chest wall
2. Anterolateral aspect of the upper arm

### If needed

- Anterior abdominal wall
- The anterior surface of the thigh

### Procedure

Insert a 20 G needle or 22 G butterfly needle or 24 G Insyte two fingers below the clavicle bone, at an angle of 30 to 45 degree under the skin into the subcutaneous tissue. (You can hold the needle just as you would insert intravenously, but instead of trying to find a vein you can easily place it in the subcutaneous plane by pinching up a fold of skin.). Connect to 3- way with extension tubing. Secure the tube with micropore adhesive. There is no need for heparin bolus.

### Points to remember

- Avoid mixing dexamethasone with other drugs in the same syringe
- Non-irritant drugs –injection sites can be used for more than seven days; if there is a recurring problem with inflammation or pain, the site should be changed prophylactically every two days.

## Hydration in Terminally ill patients

Artificial hydration should be used judiciously so as to allow maximum patient comfort. It is best administered subcutaneously. Hypodermoclysis (HDC), also known as “clysis,” is the infusion of isotonic saline into the subcutaneous (SC) space for rehydration or the prevention of dehydration.

- In ambulatory patients, common sites for SC injections include the abdomen, upper chest above the breast, over an intercostal space and the scapular area.
- In bedridden patients, the preferred sites are the thighs, the abdomen and the outer aspect of the upper arm.
- Normal saline can be delivered subcutaneously by gravity at a rate of not more than 100 ml per hour at one site; thus, about 1.5 L can be delivered at one site and 3 L at two separate sites over 24 hours.

**The average duration for which the subcutaneous cannula can be retained at a single site is 4-7 days**

## Complications

- o Tenderness
- o Hardness
- o Haematoma
- o Leakage from the insertion site
- o Swelling
- o Erythema
- o Displacement of the needle

## General Instructions

- A strict aseptic technique to be followed
- Do not aspirate before injecting
- Do not recap the needle discard immediately into the sharps container
- Do not bend, break or handle needles with hand
- If needle prick occurs, squeeze area and swab with the spirit (70%)
- Report immediately

## Patient and family education

- Explain the drug action and what for it is administered

- Loading technique
- How much to take for the administration
- Ensure that drugs being delivered are safe to use and can be used at home setting
- Thorough patient assessment is important
- Careful inspection of the site every day for signs of inflammation

#### **Precautions for biohazard patient (HIV/AIDS/ HEP B/C)**

- o Use gloves and disposable syringe and needle
- o Replace articles in the designated disposable unit after the procedure (Separate needle from a syringe using artery clamp)
- o Do not recap the used needle, Discard immediately into 'sharp' container

#### **Care of urinary catheter**

A condom-like rubber gadget is connected to the male organ to collect urine in a bag. The bag should be kept at a level below that of the abdomen of the patient. Empty the bag before it gets filled up. Condom catheters are external catheters that are worn around the penis to drain the urine into the collection bag.

#### **Situations in which condom drainage can be used:**

- Urinary incontinence
- Overactive bladder
- Incontinence due to dementia and mobility-related issues

#### **Situations in which condom drainage cannot be used:**

- Urinary retention
- Urinary obstruction

#### **Advantages of condom catheters:**

- Condom catheters are non-invasive
- Less chance of urinary tract infection when compared to indwelling catheters
- Less expensive
- Simple to use

#### **Application and care of condom drainage:**

Choosing the right size: Condom catheters are available in three sizes – Large, Medium and Small. Choosing the right size prevents leakage and discomfort.

### **Condom catheter application:**

- a) After choosing the correct size catheter, roll the catheter up to the tip (Figure 34)
- b) Clean the penis with the wet cloth from the urethral orifice in a circular motion towards the shaft of the penis and leave it to dry.
- c) Gently insert the foreskin/glans penis into the condom and unroll the condom over the shaft of the penis.
- d) Apply Velcro strap/adhesive tape around the condom to secure it in place. Ensure that it is not too tight that it obstructs the urinary flow or too loose that it slips out of the penis.
- e) If an adhesive tape is used to secure the condom in place, ensure that it is applied only around the condom and not around the skin (Figure 35). Adhesive tape should not be used around the skin as it can cause pain and injury upon removal.
- f) Connect the urine collection bag to the tip of the condom catheter to facilitate drainage.

### **Nursing care for the patient with a urinary catheter**

#### **Care of Catheter**

- Wash your hands before and after touching the patient/catheter
- Keep the urine bag at a level below that of the lower abdomen
- Empty the bag before it reached 3/4th
- Clean up the opening of the penis or vulva where the catheter is inserted with soap and water and dry cloth
- Keep the patient clean and dry

#### **Preventing Infection**

- Clean your hands before and after touching the catheter or bag
- Keep the drainage bag below the level of your bladder and off the floor at all times
- Keep the catheter secured to your 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

#### **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

### Health Education

- 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. 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.
- Instruct the patient and the family caregivers to inform 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.

## Chapter 12:

# Palliative Care in HIV/AIDS

### Learning objectives:

- 1) Explain the importance of palliative care in HIV/AIDS management
- 2) Elaborate on the socio-medical issues in HIV/AIDS
- 3) Explain the symptom management in HIV/AIDS

### Introduction

Cumulative experience and increased awareness have led to the use of prophylaxis, earlier diagnosis, and more effective treatments for HIV itself with antiretroviral drugs. In addition, the many complications of HIV infection and AIDS are now more effectively managed. As a result, patients with HIV now have improved survival but are more likely to experience months or years of increasing dependency, punctuated by episodes of acute illness.

### Why palliative care for people with HIV/AIDS?

- Dramatic changes in HIV/AIDS care in the past decade
- Increasing body of knowledge and expanded definition of palliative care
- Shift in the trajectory of dying from HIV/AIDS
- Patients with HIV/AIDS have palliative care needs at every stage of the illness
- Good pain and symptom management can increase adherence to ART and other treatments.

### HIV/AIDS: Pre-ART era

- Rapidly fatal course at the end
- Emphasis on treating opportunistic infections and on providing palliative care
- Physicians and other care providers received specific training in end of life care

### HIV/AIDS in the ART era

- Chronic, manageable disease for many
- Unpredictable course with more prognostic uncertainty
- Complex treatment regimen requiring specific expertise
- Multiple symptoms with complex etiologies
- Focus of care and training on ART and not on palliative care

### Importance of palliative care in HIV/AIDS

- Co-morbidities of Hepatitis B & C and malignancies can be fatal

- ART is not a cure and has many side effects
- Many symptoms throughout the disease affect quality of life
- Complex psychosocial issues such as psychiatric illness and substance abuse
- HIV/AIDS disproportionately affects minority and marginalized populations
- These groups often enter care later in the disease progression
- Some groups have less access to ART
- Gaps in the support system to adhere to a complicated medication regimen

### **The scope for palliative care in HIV/AIDS**

- Like in any other chronic illness, palliative care in HIV/ AIDS need to be integrated with disease-modifying therapies.
- The focus is on quality of life with due attention to the multidimensional factors -physical, social, emotional, spiritual etc. - which contribute to it. As would have been in any other condition receiving palliative care, the approach should be patient and family centred.
- The specific medical issues in palliative care of AIDS patients include multiple infections, chronic suppressive therapies, increased risk of adverse drug reactions, need for continued prophylaxis and multiple medications.
- They also have a myriad of psychosocial issues. Most are young people from marginalised or minority groups.
- Often there will be multiple infections (and multiple deaths) in the family affecting effective care at the family level.
- The social stigma for HIV/AIDS is high, and this raises the issue of confidentiality of these patients.

### **Clinical care services:**

- Prevention and treatment of TB/HIV
- Prevention and treatment of other Opportunistic Infections (OI)
- Alleviation of HIV-related symptoms and pain
- Nutritional rehabilitation for malnourished PLHA
- Psychological care:
  - Mental health counselling o Support groups
  - Diagnosis and treatment of HIV related psychiatric illnesses, depression and related anxieties
  - Bereavement services
- Spiritual care:
  - This includes culturally sensitive services that support individuals and families through faith and rituals.
- Supportive care:
  - Assists individuals and families to link with the following services:

- Child care
- Adherence to treatment
- Legal services - rights, inheritance o Housing
- Food support
- Income Generation Program
- Prevention Services
- Interventions for serodiscordant couples including VCT and ongoing counselling Community and clinic-based support groups
- Case management and provider delivered prevention messages focused on disclosure
- Correct and consistent use of condoms and mutual fidelity

Problems & Possible causes	Effect on Health
Diarrhoea	Life-threatening due to dehydration and electrolyte imbalance
Malignancies like Kaposi's sarcoma, lymphoma	Significant weight loss
Dyspnoea - Due to chest infection or anaemia	Shortness of breath on slight exertion and fatigue
Anorexia	Refuses food. Gets bony and thin.
Skin and mucous membrane lesions	Ulceration, soreness on the affected part
Visual problems	Diminished vision or blindness that in turn affects activities of daily living
Neurological impairment	These may have physical and cognitive aspects such as peripheral neuropathy, ataxia
Progressive weakness, Immobility	Misconception, unable to accept the sickness
Ignorance	Dependence
Apprehension, Fear, Social and emotional issues	Isolation, loss of job

## Nursing Care of Patients with Symptomatic HIV

### Goals and objectives

- To relieve symptoms and maximize the level of functioning and quality of life
- To relieve physical discomfort
- To provide emotional support
- To train the patient and family regarding self-care by actively participating in the care plan
- To aid in the acceptance of sickness and its consequences
- To provide counselling regarding healthy living

### Symptom management in HIV/AIDS

- Pain in HIV:

The number and incidence of pain increases with disease progression and more than 80% of the hospitalised patients with AIDS complain about pain.

### **The common causes are**

- Due to HIV infections: neuropathy, arthropathy, aseptic meningitis, infections with fungi, bacteria, virus or protozoa, Kaposi's sarcoma and lymphomas.
- Due to treatment: Procedures, ART causing neuropathy or myopathy, pancreatitis etc. and radiotherapy for malignancies.
- Due to debilitation: Pressure sores, constipation, musculoskeletal pain from wasting and inactivity. Treatment may involve using analgesics according to the WHO Analgesic Ladder (please refer the section on pain management), adjuvant analgesics, disease-specific therapy and psychosocial support etc.
- Wound care: The people with HIV/AIDS develop wounds from infections, malignancies etc. Please refer the section on wound care for more details.
- Loose stools: Treat with Oral Rehydration Solution and if without a frothy stool, blood and mucus Tab. Loperamide, 2mg, after each episode of loose stool, can be given. If there are frothy stool, blood or mucus then treat with Tab. Metronidazole 400 mg TID for 14 days.
- Fatigue/wasting: This is a difficult symptom to treat. In suitable patients, ART may revert the situation. In the later stage of the disease, even good nutritional supplements are unlikely to help, and this may have to be explained.
- Treating specific conditions: There are some situations where aetiological management should be considered if such intervention will improve the quality of life of the patient and not put an undue burden on him/ her. Many opportunistic infections (like candidiasis, tuberculosis) skin conditions; bacterial pneumonia etc. can be effectively managed even in patients with reasonably advanced diseases.

### **Nursing care for a patient with HIV/AIDS**

**Comprehensive palliative care is essential to the health and well-being of people living with HIV/AIDS (PLHA).**

#### **Diarrhoea**

- Skincare after each bowel movement
- Pat and dry with a soft cloth, apply vaseline
- Assess for excoriations of skin or inflammation
- Encourage frequent fluid intake and a small quantity of low fibre diet
- Administer anti-diarrhoeal drugs as per need
- Assess for faecal impaction

#### **Nausea and vomiting**

- Administer anti-emetics 30 minutes before meals
- Do not give anything orally after vomiting for 2 hrs
- Provide oral hygiene

#### **Fever**

- Monitor temperature once in every four hours

- Administer antipyretics
- Encourage fluid intake
- Give tepid bath

### **Dyspnoea**

- Comfortable position to relieve dyspnoea.
- Relaxation techniques
- Teach patient to take medicines promptly

### **Pain**

- Assess the location and intensity of pain
- Administer analgesics as per order
- Light massage and hot fomentation for muscle pain

### **Cognitive impairment**

- Assess mental status
- If confused, speak in a calm manner
- Avoid disagreement with the patient
- Prevent injury by keeping the environment clean
- Use memory cues
- Provide family support

### **Fatigue and weakness**

- Involve patient in planning
- Encourage frequent rest periods
- Identify supportive devices (such as commode)
- Supervise family care in maintaining hygiene

### **Skin breakdown**

- Reposition every 2 hours and keep skin clean and dry
- Moisturize skin with coconut oil
- Manage the pressure points
- Assess the skin for redness

- Provide mouth care at 4-hour interval
- Educate about wound care

### **Depression**

- Talk to the patient and allow expression of their fear and concern
- Involve the patient in planning and providing for their care
- Identify the patient's interest

### **Knowledge deficit**

- Assess caregiver's environment and understanding of HIV and its transmission
- Safe sex practices
- Universal precautions
- Keep the environment clean

### **Nursing care issues**

- Care depends upon the hospital policies and procedures
- routinely followed for infection control.
- Use safety precautions
- Use gloves and apron while collecting blood and other body fluids for laboratory investigations
- Safe disposal of syringes, needles and other articles used by the patient.
- Isolation of terminally ill patients and patients having active tuberculosis
- Ensure confidentiality
- Medical staff, family members, social service counsellors and friends should be part of the support system providing physical care for the patient
- Administration of medical treatment, where Community Health Officer should have the knowledge of the drugs used, its side effects, route of administration and indications

### **Conclusion:**

Palliative care has traditionally been associated with terminal or end-of-life care. However, current thought and practice take the broader view that palliative care encompasses care provided from the time that HIV is diagnosed and throughout the continuum of HIV infection.

## Chapter 13:

# Care of Dying

### Learning objectives:

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

- 1) Elaborate on how to recognize that a patient may be dying, aware of general principles in looking after a dying patient
- 2) Explain how to provide death care.

### Group activity

- 1) Instructions: Elicit a list of symptoms during the terminal phase of life the participants have seen/heard of.
- 2) What are the physical problems that you see in a dying person?

### Introduction

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

Terminal Care refers to the management of patients during their last few days, weeks or months of life, from a point at which it becomes clear that the patient is in a progressive state of decline.

‘Dying process’ is prolonged due to the increasing burden of non-communicable diseases, an increase in life expectancy and improvement in medical technology. The main aim of terminal care is to make the dying process comfortable for the patient. This will mean shifting the goal of care from preserving life to providing comfort in dying

Good death” is one that “is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes and reasonably consistent with clinical, cultural and ethical standards.”

### 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 to be described here are happening to a person whose 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 nutritional requirement of the body comes down drastically. So, the person may have decreased appetite and decreased thirst.
- It is essential to keep in mind that this is a natural process, and it is not distressing to the patient. But it may be uncomfortable for the family caregivers to see the patient not eating or drinking fluids.
- Reassuring them and encouraging them to provide sips of water and applying moist swab on lips can promote the comfort of the patient, on the other hand forcing feeds may increase the patient 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 now is to avoid routines that make the person uncomfortable and provide care that is aimed at improving comfort.

**Increasing drowsiness:**

- As a patient moves into the End of Life phase, he/she becomes increasingly tired, drowsy, and difficult to arouse. The time spent sleeping gradually increases.
- There may be decreased speech, and they may appear withdrawn.
- In some patients, there may also be confusion, inability to recognise 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, the respiration becomes shallow.
- In some patients, the respiratory rate may increase, but usually, the respiration becomes shallow and spaced out.
- Jaw breathing can be seen in some patients.
- Carers should be reassured that this is a typical process of dying, and it is not distressing to the patient.

- Another distressing symptom for the family carers to watch is 'death rattle'. It occurs due to the accumulation of salivary secretion and mucus at the throat as swallowing and coughing reflex 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 to the patient.
- It can be managed effectively by turning the patient to the sides and draining the secretions. Anticholinergics like glycopyrrolate given sublingually or subcutaneously can reduce these secretions.
- The secretions that have collected already 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 decreasing 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 he/she is 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 a priority at this point.
- Maintaining good perineal hygiene and prevention of pressure sores is crucial to maintain 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,, breathlessness, dyspnoea according to Unitary 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 him/ her respite.
- Check that nursing care for the patient with attention to oral hygiene, skin, bowel and bladder care is continuing.
- Remain sensitive to the changing physical and emotional needs of the patient and family.

## Death Certification

- Any doctor preferably from the treating unit, can certify death. He/she should Diagnose and declare the death
- Inform the relatives
- Certify death & fill the necessary forms
- Seek permission & arrange for autopsy, if necessary
- Assist the family in decisions regarding transportation, embalming, mortuary care, etc

## Last office/death care

### Purpose:

- To maintain normal body alignment before rigour 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

## Care after Death

The first hour after death can be very peaceful.

1. Family can feel sadness but also a deep sense of relief, especially if the patient has 'suffered'
2. If possible, encourage the family to have time and space
3. When the moment is right, remove any medical equipment such as syringe driver, catheter, nasogastric tube.

4. Replace dentures if the patient has been using dentures
5. Give a thorough bath and remove secretions, discharge and bloodstains
6. Apply jaw bandage so that the mouth is kept closed
7. Plug orifices (nose, mouth, vagina, and rectum) with absorbent cotton followed by non – absorbent cotton
8. Close eyes with by keeping a wet cotton ball on closed lids
9. Facilitate any religious, spiritual or cultural needs
10. Clear room of unnecessary clutter and use a clean cloth to cover the patient

## Chapter 14:

# Service delivery framework and Role of Community Health Officer in Palliative Care

### Introduction

Community Health Officers play multiple roles under Clinical, Public Health and Managerial functions. A well-trained CHO in palliative care can extend quality care to patients and coordinate their care at home and Sub Health Center. They also empower the patients and their caregiver(s) with ongoing care at home.

### Roles of Community Health Officer in Palliative Care

#### Clinical functions:

- You will conduct detailed assessment of patients/family identified by ASHA through home visits using screening tool and home visit care sheet (Annexure 1,3)
- You shall refer patients with high pain score (pain score of 6 and above) to the PHC-HWC for pain management.
- You shall provide basic nursing care to palliative care patients, and perform necessary nursing procedures in required cases.
- Home-care should also be provided to those patients seeking exclusive AYUSH treatment.

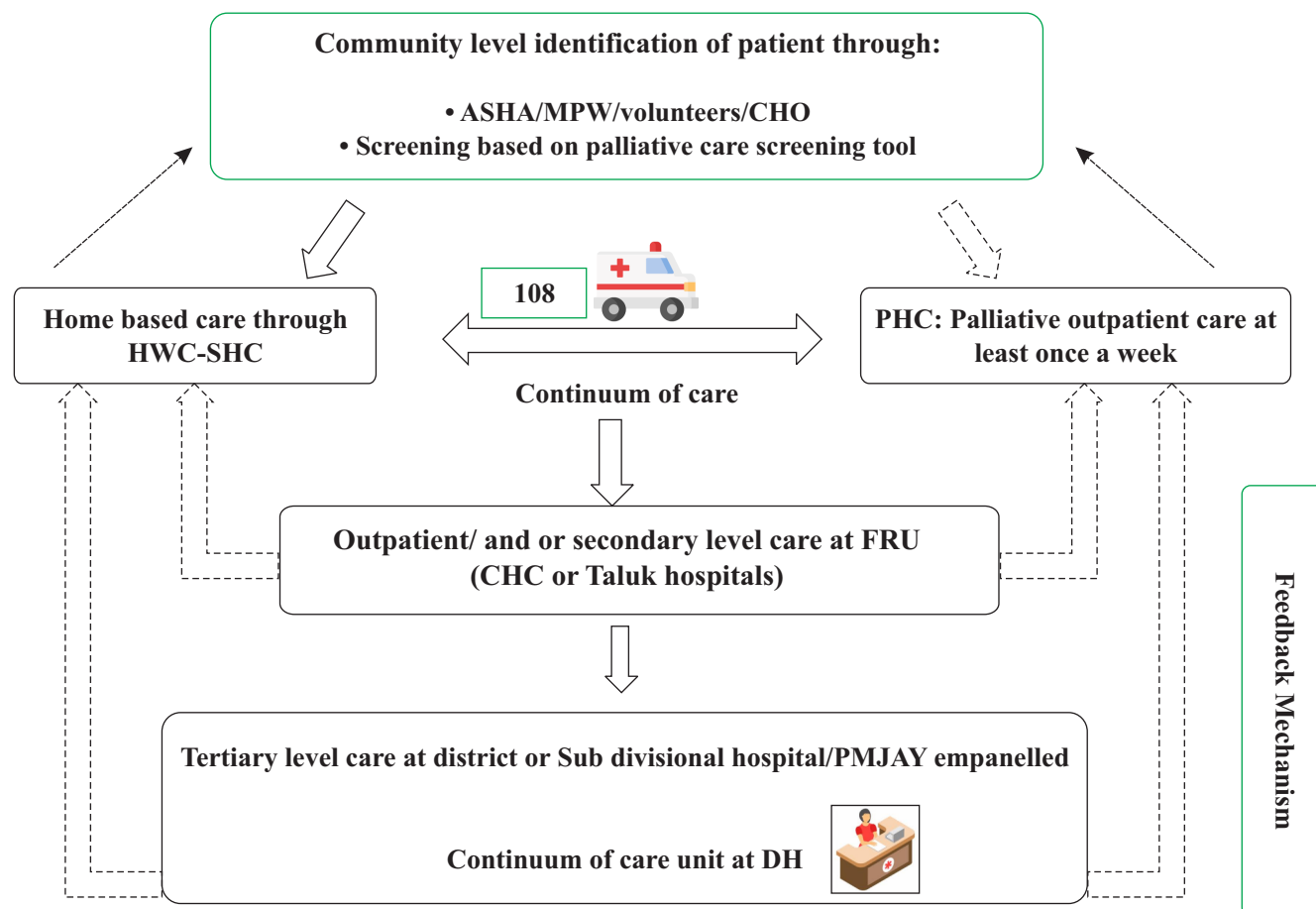
#### Public health functions:

- You should take the leadership in creating Patient Support Groups and Care givers Support Groups with community volunteers. It is recommended that the group should be convened once in a month and the meeting shall be presided by the CHO.
- You will undertake social and behaviour change communication effort in general community and specific groups (teachers, panchayat members, NGOs, youth groups and women self-help groups) in order to recruit volunteers for palliative care services in her/his HWC coverage area.
- You can undertake a social behaviour change communication training of volunteers from the community at HWC- SHC.
- You, along with the MPW, ASHA and Volunteers, shall take pro-active steps to avail benefits from various government and non-governmental programs/schemes to the eligible patients/ caregivers.

#### Managerial functions:

- You shall supervise the SHC-HWC team in identifying and line listing of individuals requiring palliative care support.
- You shall maintain relevant records of the palliative care patients in your area, including referral and follow-up records.
- You will be provided a 'palliative-care kit' (Annexure 4) containing necessary drugs and consumables, which you can use for providing palliative care. You shall maintain inventory control for the same.
- You shall maintain a list of such hospices and trained palliative care physicians in the neighbourhood and up to the district with all contact details. The same shall be provided by the District Program Officer. You can publicise it for the benefit of the people in your area.

## Referral Pathway for patients in need of Palliative care



## Service Delivery framework of Palliative Care

Care at Community Level	Care at SHC-HWC	Care at PHC-HWC	Care at secondary / tertiary care facility
<p>Awareness generation and community mobilization (MPW, CHO and ASHAs)</p> <ul style="list-style-type: none"> <li>• Create awareness about palliative care, first level screening of patient/families for potential palliative care needs</li> <li>• Home visits to the patients and provide psycho-social support to the families/patient (ASHA, Community volunteers)</li> <li>• Linkage with community platforms, specific groups to raise awareness about the</li> </ul>	<p>Community Health Officer</p> <ul style="list-style-type: none"> <li>• Support Home Based care</li> <li>• Provision of “Palliative care kit” and.</li> <li>• ensuring home based care for patients seeking exclusive AYUSH treatment.</li> <li>• A list of hospices and trained palliative care physicians in the neighbourhood with their contact details will be maintained and</li> </ul>	<p>Medical Officer (MBBS)</p> <ul style="list-style-type: none"> <li>• Provision of providing Palliative care Out Patient services at least once a week</li> <li>• Prescribing appropriate drugs, including Oral Morphine and maintaining separate case sheet and patient card for palliative care patients</li> </ul>	<p>CHC-MOIC</p> <ul style="list-style-type: none"> <li>• Provision of a dedicated palliative care Out Patient services at least once in a week for walk-in patients and those referred from PHCs/UPHCs.</li> <li>• At least 5 beds to be earmarked for palliative care patients as apart of providing inpatient services.</li> <li>• Ensuring continuum of care at the hospital, at</li> </ul>

<p>needs of palliative care patients and mobilize individual and community level support</p> <p><b><u>Screening and Identification</u></b></p> <ul style="list-style-type: none"> <li>• Identification of bed ridden patients and others needing palliative care and refer to CHO.</li> <li>• Screening and Early Detection of the identified individuals using Palliative Care screening tool</li> <li>• Identification of community volunteers.</li> <li>• Support family in identifying behavioral changes and providing care in elderly.</li> <li>• Identifying group of volunteers to be trained in simple nursing skills.</li> <li>• Monthly report submission based on the format of palliative care services</li> </ul>	<p>shared with the community</p> <ul style="list-style-type: none"> <li>• Provision of services of Yoga trainer and ICTC counsellor at the PHC-HWC to enable supportive supervision of the palliative care team at the Sub Centre –HWC.</li> <li>• Providing “out of hours” care to those experiencing the final days of their life (End-of-life-care) and the death is duly reported to the HWC – PHC/UPHC.</li> <li>• Provision of bereavement support after the death of the patient.</li> <li>• Ensuring social support by availing benefits from government and non-governmental programs / schemes to the eligible patients/ caregivers and to be displayed at the HWC.</li> <li>• Creating Patient Support Groups and Care givers Support Groups with community volunteers and ensuring to convene the meeting once in a month presided by the CHO.</li> </ul>	<ul style="list-style-type: none"> <li>• Provision of home care and end of life care palliative care services for those who need it, on a routine or emergency basis as required.</li> <li>• Necessary sensitization session should be carried out under the leadership of MO for caregivers, general public, representatives from PRI/Urban Local Bodies (ULB), students etc as these platforms are to generate volunteers and impart basic patient management and communication skills to volunteers, caregivers etc.</li> <li>• Ensuring referral services for secondary level of palliative care</li> </ul>	<p>higher level centre like District hospital and at home too as per the need of the patient.</p> <ul style="list-style-type: none"> <li>• Facilitating referral to district hospitals when needed</li> <li>• Monitoring and supervision of activities of PHCs/UPHCs</li> </ul> <p>District Hospital/Sub Divisional Hospital level</p> <ul style="list-style-type: none"> <li>• Provisions of OPD consultations geared at formulating a treatment / intervention plan and receive a prescription accordingly.</li> <li>• Involvement of a trained medical social worker/ counsellor / psychologist to ensure counselling/ psychosocial interventions / psychoeducation The ICTC counsellor at the PHC shall be trained and deputed to extend this support wherever available.</li> <li>• Ensuring inpatient treatment services including psychosocial and spiritual interventions, recreation facilities and formulating the plans for home based palliative care by involving patients and care givers</li> <li>• Provision of Follow up from the OPD.</li> </ul>
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## Further Reading

1. Handbook for Health Care Workers, National Programme for Palliative Care, Government of India.
2. Palliative Care-A workbook for Carers, Institute of Palliative Medicine, Calicut, Kerala, 2017
3. Home-Based Palliative Care A Manual for Nurses, WHOCC for Community Participation in Palliative Care and Long Term Care, 2020
4. Foundation Course In Palliative Medicine-A Manual, Sanjeevan Palliative Care Project, Puducherry
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10. Handbook for Certificate Course in Essentials of Palliative Care, Indian Association of Palliative Care, Fifth Edition, 2017
11. Global Conference on Primary Health Care, World Health Organization and the United Nations Children's Fund (UNICEF), 2018
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13. The Need of the Hour, Palliative Care Handbook, Dr Asoke Chackalackal Mathew, Search Foundation, Chennai, 2018
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15. Ayushman Bharat: Comprehensive Primary Health Care through Health and Wellness Centers: Operational Guidelines, NHSRC
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18. Goyal M. Role of Ayurveda in end-of-life care. *Ayu*. 2019 Jan-Mar;40(1):1-2
19. Palliative Nursing Improving end of life care, Shawn Kinghorn, Sandra Raines, 2nd edition, Bailliere, Tindall, Elsevier, 2007, Churchill Livingstone
20. Oxford textbook of Palliative nursing 3rd Edition, By Betty R. Ferrel, Nessa Coyle, Oxford University Press, 2010

## Annexure

Annexure 1: Suggested Screening form for ANM

Name of ASHA Personal Details		Village Part
Name of ANM		Sub Centre/ Health & Wellness Centre
PHC		Date
Name		Any Identifier (Aadhar Card, UID, Voter ID)
Age _____		RSBY beneficiary: (Y/ N )
Sex		Telephone/ Mobile No.
Address :		
	<b>Screening Items</b>	<b>Points</b>
1	Presence of metastatic or locally advanced cancer	2
2	Functional status score, according to ECOG/WHO performance status score Normal & Asymptomatic Symptomatic, able to do Normal Work as pre-diseased Symptomatic, able to do activities of Daily life without assistance Needs assistance with ADL, Limited Mobility Bed ridden, Totally dependent on others for ADL	0 1 2 3 4
3	Surprise Question: Will you be surprised if this individual died in next 6 month Yes / No	0 / 2
4	Presence of one or more serious comorbid diseases also associated with poor prognosis (eg, moderate-severe COPD or CHF, dementia, AIDS, end stage renal failure, end stage liver cirrhosis)	1
5	Presence of palliative care problems	
	Symptoms uncontrolled by standard approaches	1
	Moderate to severe distress in patient or family, related to cancer diagnosis or therapy	1
	Patient/family concerns about course of disease and decision making	1
	Patient/family requests palliative care consult	1
	Total score (0-13)	
Cut off of 5 or more can be used for referral for palliative care services		

**Annexure 2: Suggested format for documentation of Palliative Care Services**

<b>Patients with palliative care needs</b>						
<b>Sr.No.</b>	<b>Name</b>	<b>Age/Sex</b>	<b>Diagnosis</b>	<b>Functional Diagnosis*</b>	<b>Screening score</b>	<b>Referral Yes/ No</b>
1						
2						
3						
4						
5						
<b>Home care visits</b>						
<b>Sr. No.</b>	<b>Name</b>	<b>Age/Sex</b>	<b>Diagnosis</b>	<b>Functional Diagnosis*</b>	<b>Accompanied by</b>	<b>Main interventions</b>
1						
2						
3						

	Sensitization/ IEC activities					
Sr.No.	No. of beneficiaries	Venue	Resource person		Type of beneficiaries	Method used
1						
2						
3						

\* With respect to Activities of Daily Living(ADL) - Independent/ Minimal support required/ Bed ridden

### Annexure 3: Home visit case sheet

1. Name: \_\_\_\_\_ Age: \_\_\_\_\_ yrs Sex: \_\_\_\_\_ Religion: \_\_\_\_\_

2. Date of first contact with family: \_\_\_\_\_

3.

Address:	Telephone	Useful info/ remarks-route with distance, landmarks etc.
Other contact name & Address:		

4. Informant, if other than patient:

Relation to the patient:

5. Family tree:

Other relevant family related info:

6. Social background:

Occupation : Current	Before illness
1. Self-employed	1. Self-employed
2. Employee	2. Employee
3. Unemployed	3. Unemployed
4. Retired	4. Retired
5. Student	5. Student
6. Homemaker	6. Homemaker
7. Other	7. Other

No. of members in the family: \_\_\_\_\_ Earning family members: \_\_\_\_\_

Any other family member with chronic disease (details):

Primary care giver: \_\_\_\_\_ Other support : \_\_\_\_\_

Availability of government scheme cards : BPL / APL / Ayushman Bharat / State Specific cards

7. Diagnosis: [Include all the diseases/ disabilities]

8. Treatment Status:

Ongoing treatment:

Previous treatment/s for this condition:

ECOG performance status:

0- Normal activity	1- Ambulatory + Light work	2- Ambulatory Self Care [No work]
3- Limited Self care / Confined to bed or chair mostly	4- Completely disabled, No self care	

General condition	Fairly good / Poor / Debilitated / Very weak / Drowsy / Unconscious/ Terminal state
Communication	Easy / Occasionally / Withdrawn / Non - communicative
Main concerns	
Sleep	Normal /Disturbed /Wakeful nights (reason)
Urination	Normal / Hesitancy/ Increased frequency / Incontinence / on catheter
Bowel	Normal /Diarrhoea / Constipation /Stoma
Malodour	Due to incontinence/ Infected ulcer
Appetite	Good / Fair / Poor / None

Present symptoms: (by patient / informant)

Pain	Sore mouth	Itching
Nausea	Swelling	Agitation/ irrelevant talk
Vomiting	Ulcer/ Wound	Tiredness
Swallowing difficulty	Bleeding	Drowsiness
Heart burn	Lymphoedema	Others (List below)
Constipation	Pressure sores	
Loose motions	Urinary problems	
Cough		
Breathlessness		

Most distressing symptoms:

Social and emotional issues:

Spiritual issues:

Psychological assessment:

	Patient	Family
Insight about Disease	Complete / Partial / No	Complete / Partial / No
Insight about prognosis	Complete / Partial / No	Complete / Partial / No
Acceptance of the conditions	Complete / Partial / No	Complete / Partial / No

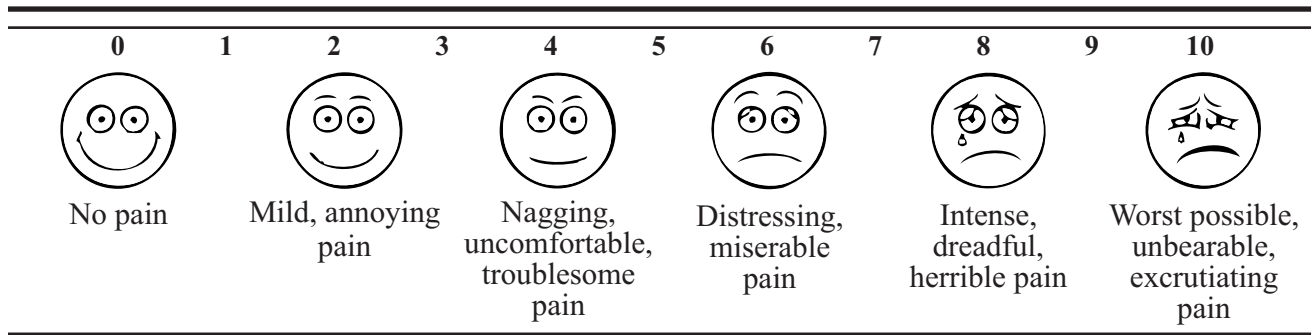
Pain Assessment:

- Patient has no pain.

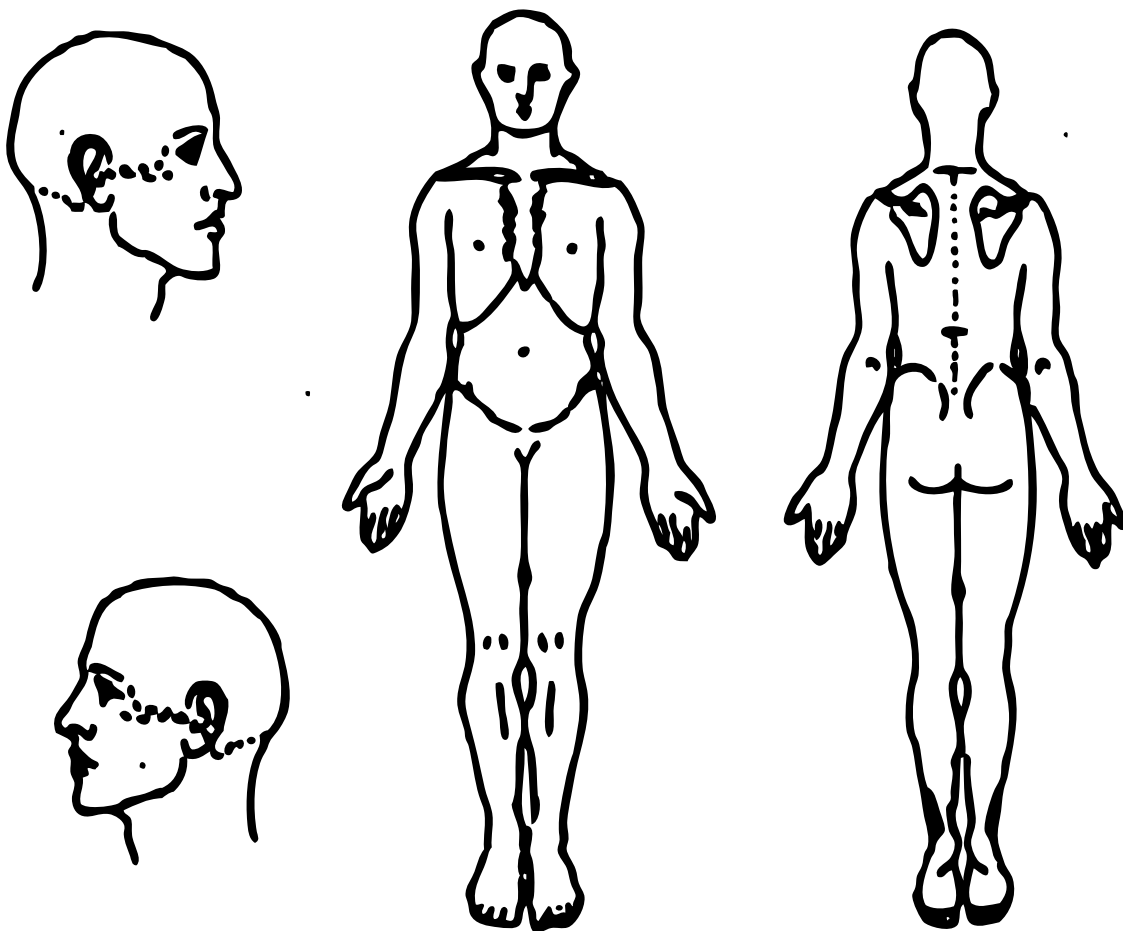
Effectiveness of present pain medicine: Good / Fair / Poor / not on any pain medication

Site	Intensity (0-10)	Duration	Type (Constant/ Intermittent)	Character (Aching/ Throbbing / Burning / Pricking/ Lanciating)	Provoking/ Palliating factor
A					
B					
C					

(A) Mark the pain Intensity



(B) mark the location of pain (e.g., A,B,C.....)



**Brief Management Plan:**



#### Annexure 4: Follow up case sheet

Name of the patient: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_ Date: \_\_\_\_\_

Type of visit: Routine /Emergency

ECOG performance status: 0 / 1 / 2 / 3 / 4

General condition	Fairly good / Poor / Debilitated / Cachectic / Very weak / Drowsy / Unconscious/ Terminal state
Feeling	Good /Comfortable / Bad /Amgry/ Sad / Anxious/ Depressed Patient says:
Communication	Easy / Occasionally / Withdrawn /Non- communicative
Ambulation/ Activity	Normal activities / Limited activities (needs support) / Needs assistance for ADL/ Bed bound
Main concerns	
Sleep	Normal /Disturbed /Wakeful nights (reason)
Urination	Normal / Hesitancy/ Increased frequency / Incontinence / on catheter
Bowel	Normal /Diarrhea / Constipation /Stoma
Maldour	Due to incontinence/ Infected ulcer
Appetite	Good / Fair / Poor / None

Present symptoms: ( by patient / informant)

Pain	Sore mouth	Itching
Nausea	Swelling	Delirium
Vomiting	Ulcer	—
Swallowing difficulty	Bleeding	Tiredness
Heart burn	Lymphoedema	Drowsiness
Cough	Pressure sores	Others (List)

Most distressing symptoms:

Distress level:

Social and emotional issues:

Spiritual issues:

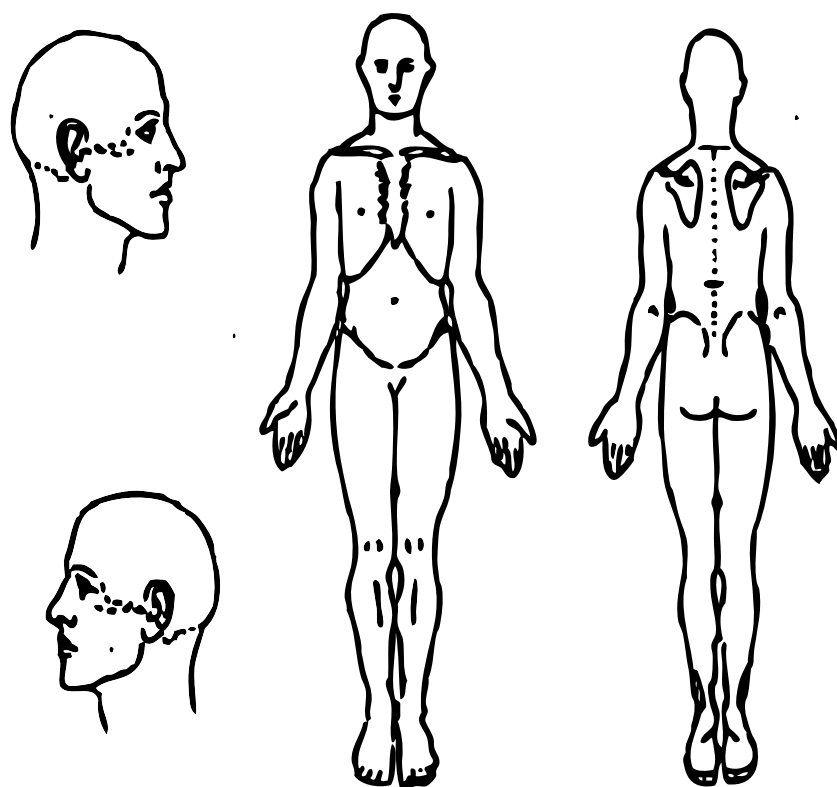
Pain Assessment:

• Patient has no pain.

Family's input same / different

Effectiveness of preset pain medicine: Good / Fair /Poor / not on any pain medication

Site	Intensity (0-10)	Duration	Type (Constant/ Intermittent)	Character	Provoking/ Palliating factor
A					
B					
C					
D					



Systemic Examination:

Treatment advised (Pharmacological & Non-pharmacological):

## Annexure 5: Suggested Palliative Care Screening Tool for Community Health Officer/Staff Nurse/Medical Officer

\*\* To be assessed by a trained Medical Officer

Name of ASHA	Village Part	
Name of ANM	Sub Centre	
PHC	Date	
Name	Dependent (financially): Yes / No	
Number of earning members in the household: Number of children (under the age of 18 years):	Any Identifier (Aadhar Card, UID, Voter ID)	
Age _____	RSBY beneficiary: (Y/ N )	
Sex	Telephone/ Mobile No.	
Address :	Undergoing treatment from:	
Date of diagnosis Diagnosis:		
	<b>Screening Items</b>	<b>Points</b>
1	Nature of serious health related suffering including diagnosis (India SHS screening tool – see below)	2
2	Functional status score, according to ECOG/WHO performance status score <ul style="list-style-type: none"> <li>• Normal &amp; Asymptomatic</li> <li>• Symptomatic, able to do Normal Work as pre -diseased</li> <li>• Symptomatic, able to do activities of Daily life without assistance</li> <li>• Needs assistance with ADL, Limited Mobility</li> <li>• Bed ridden, Totally dependent on others for ADL</li> </ul>	0 1 2 3 4

3	Presence of one or more serious comorbid diseases also associated with poor prognosis (eg, moderate -severe COPD or CHF, dementia, AIDS, end stage renal failure, end stage liver cirrhosis)	1
4	Presence of palliative care problems	
	• Symptoms uncontrolled by standard approaches**	1
	• Moderate to severe distress in patient or family, related to cancer diagnosis or therapy	1
	• Patient/family concerns about course of disease and decision making	1
	• Patient/family request s palliative care consult	1
	Total score (0 -13)	
<i>Cut off of 4 or more will be considered for referral for palliative care services</i>		

**NCG - SHS Tool for Field Testing**

Domains of Health-related Suffering	Not at all Score 0	A little Score 1	A lot Score 2
<b>Associated with your health, do you suffer physically?</b> With pain/ breathing difficulty/ vomiting/ constipation/ weakness / feeding/loose motion/ bleeding/ itching/ wounds /difficulty with senses (see, hear, smell, touch, taste) / difficulty moving/ other issues			
<b>Associated with your health, do you suffer emotionally?</b> Feeling sad/ unloved / worried/ angry/ lonely/ difficulty sleeping/ confused/ poor memory / other issues			
<b>Associated with your health, do you suffer due to</b> issues with family/ relationships/ friends/ community/ feeling isolated/ difficulty at work/ difficulty with hospital visits/ difficulty communicating/ other issues			
<b>Associated with your health, do you suffer due to</b> feeling punished/ fearful/ shame / guilty / angry with God / no meaning to life/ disconnected/ other issues			
<b>Associated with your health, do you suffer due to</b> lost job/ stopped studies/ stopped working/ loan / debt/ sold property/ sold assets / migrated out / other issues			
Is there Presence of <b><u>Health-related Suffering</u></b> ?	Total Score $\geq$ 2 <b><u>YES</u></b>		Total Score < 2 <b><u>NO</u></b>
<p><b>If <u>YES</u>:</b> Is the health-related suffering <b><u>Serious</u></b>?</p> <p><b>Has this suffering limited you from doing what you need to do, for <math>\geq</math> 14 days over the last 30 days?</b> e.g. self-care (feed, bathe, dress, walk, toilet); care for others; communicate; learn /think/perform duties; sleep / rest?</p>			

<b><u>YES.</u> (<input checked="" type="checkbox"/> SHS)</b>		<b><u>NO.</u> (<input type="checkbox"/> SHS)</b>
<b>1.</b> Document as ‘ <b>Patient has screened positive for <u>Serious</u> Health-related Suffering</b> on the case file, notify and activate further evaluation by the primary treating team <b>2. Ask the patient</b> – Do you seek more help for your concerns?		The screening for SHS is continued at quarterly intervals.
<b><u>YES, I seek help</u></b>	<b><u>NO, I do not seek more help</u></b>	
Activate further evaluation and care-pathways to respond to SHS <sup>1</sup>	Educate patient/family on how to seek additional support in case they feel the need for it and empower with the	

<sup>1</sup> See referral chain in the guidelines

## Annexure 6 : Home Care Kit

For effective delivery of home-based palliative care services, the home care team will be provided a home care kit. The kit will be located in sub centre or Health & Wellness Centre. CHO will be responsible for maintain the home care kit. PHC will ensure an uninterrupted supply the contents of the kit. The contents of the kit will be procured from through existing state specific procedures. The funds for the same will be provided as part of NPCDCS budget. The suggested composition of home care kit would be as follows:

<b>Supplies</b>	<b>Medicines</b>
<b><u>Equipment</u></b> <ol style="list-style-type: none"> <li>1. Stethoscope</li> <li>2. BP Apparatus</li> <li>3. Light weight foldable stool</li> <li>4. Torch</li> <li>5. Thermometer</li> <li>6. Tongue Depressors</li> <li>7. Forceps</li> <li>8. Glucometer</li> </ol>	<b><u>Pain Control</u></b> <ol style="list-style-type: none"> <li>1. Paracetamol</li> <li>2. Ibuprofen</li> <li>3. Diclofenac</li> <li>4. Tramadol</li> <li>5. Dexamethasone (as adjuvant)</li> </ol>
<b>Supplies</b> <ol style="list-style-type: none"> <li>1. Dressing Supplies</li> <li>2. Cotton</li> <li>3. Scissors</li> <li>4. Gauze Pieces</li> <li>5. Gauze bandages</li> <li>6. Dressing Trays</li> <li>7. Gloves</li> <li>8. Micropore Tapes</li> <li>9. Syringes and Needles</li> <li>10. Condom Catheters</li> <li>11. Urine Bags</li> <li>12. Feeding Tubes</li> <li>13. Foley's Catheter</li> </ol>	<b>Wound Management</b> <ol style="list-style-type: none"> <li>1. Betadine Lotion and Ointment</li> <li>2. Metrogyl Jelly</li> <li>3. Hydrogen Peroxide</li> <li>4. Turpentine oil</li> </ol>
<b>Gastrointestinal Symptom Management</b> <ol style="list-style-type: none"> <li>1. Domperidone</li> <li>2. Bisacodyl</li> <li>3. Loperamide</li> <li>4. Oral Rehydration Salts</li> <li>5. Ranitidine</li> <li>6. Metoclopramide</li> <li>7. Dicyclomine+</li> <li>8. Hyoscine Butyl Bromide</li> </ol>	<b>Antibiotics and Antifungals</b> <ol style="list-style-type: none"> <li>1. Ciprofloxacin</li> <li>2. Metronidazole</li> <li>3. Amoxycillin</li> <li>4. Fluconazole</li> </ol>

<b>Psychological Symptom Management</b> <ol style="list-style-type: none"> <li>1. Lorazepam</li> <li>2. Amitriptyline</li> </ol>	<b>Nutritional Supplements</b> <ol style="list-style-type: none"> <li>1. Iron, Vitamin and Mineral Supplements</li> </ol> <b>Other Miscellaneous</b> <ol style="list-style-type: none"> <li>2. Spirit</li> <li>3. Lignocaine Jelly</li> <li>4. Ethamsylate</li> <li>5. Deriphylline</li> <li>6. Cough Preparations</li> </ol>
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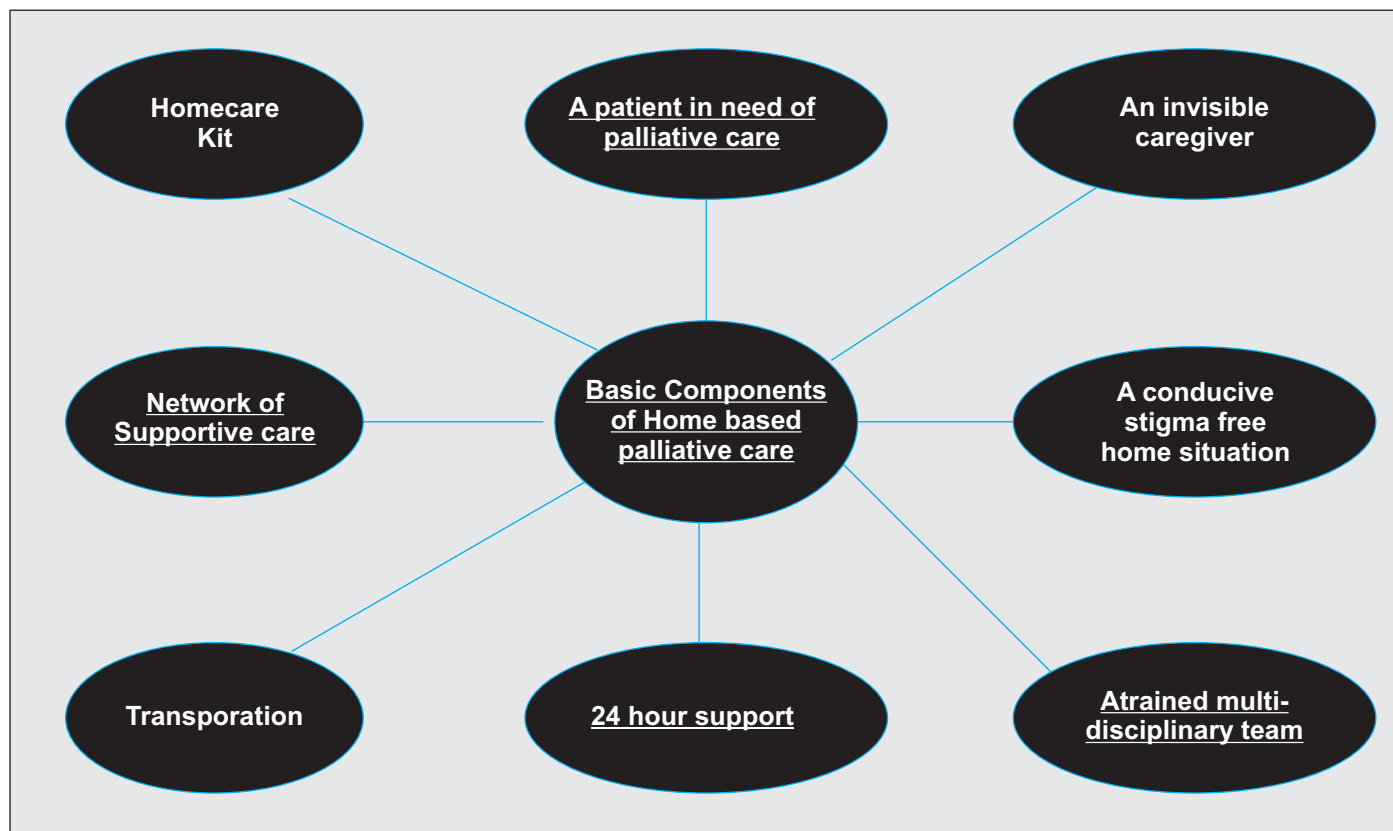
## Annexure 5: Home based care:

### Advantages of home care

Home based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence. It is also cost effective and as it does not entail travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments. Some additional advantages of home care include:

1. **Easy access to care:** The patient and family have access to advice and to all aspects of palliative care (physical, psychological, social and spiritual) at their doorstep.
2. **More effective caring:** Advice, training and additional support for the family is available so that they can become more effective in their role as care givers and feel abler to manage and cope.
3. **Access to complementary services:** The home care team can facilitate liaison with complementary and supportive services when required. The patient and family do not have to go out seeking such support on their own.
4. **Expert referrals for the patient:** The team can facilitate referral to other medical and nursing specialists involved in palliative care thereby ensuring the best possible care for the patient.
5. **Maintains confidentiality:** This is especially important for people with Cancer & HIV/AIDS who may otherwise be shunned by the community out of ignorance and due to misconceptions about the disease.
6. **Spreading awareness in the community:** Wherever appropriate, home care programmes can be used to spread awareness about palliative care. It is often the case that when a family is nursing someone with cancer their friends and associates become more aware and are more willing to discuss issues around terminal care. The family being cared for, too, can become ambassadors for the cause.
7. **Mobilising local resources:** Local support groups and volunteers can be mobilized to support patients and carers living in their particular area. They would be more willing to do this not only because they may know or have personal ties with the people affected but because it is much easier for neighbours to help each other than travel long distances to do so.
8. **Training opportunities:** Training in palliative care can be offered to medics, paramedics, community volunteers and carers in the area being covered by the home care team.

**Requirements for effective home care work.**



## References

- 1) Handbook for Health Care Workers, National Programme for Palliative Care, Government of India.
- 2) Palliative Care-A workbook for Carers, Institute of Palliative Medicine, Calicut, Kerala, 2017
- 3) Home-Based Palliative Care A Manual for Nurses, WHOCC for Community Participation in Palliative Care and Long Term Care, 2020
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- 16) Ayushman Bharat: Comprehensive Primary Health Care through Health and Wellness Centers: Operational Guidelines, NHSRC

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## NOTES

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### **Namaste!**

You are a valuable member of the Ayushman Bharat – Health and Wellness Centre (AB-HWC) team committed to delivering quality comprehensive primary healthcare services to the people of the country.

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