

# **Facilitator Guide for Community Health Workers**

डॉ. एस वेंकटेश

**Dr S. VENKATESH**

DNB, MD, DPH, MPH (Harv) FAMS, FIPHA  
Director General of Health Services



भारत सरकार  
स्वास्थ्य एवं परिवार कल्याण मंत्रालय  
निर्माण भवन, नई दिल्ली - 110 108

GOVERNMENT OF INDIA  
MINISTRY OF HEALTH & FAMILY WELFARE  
NIRMAN BHAWAN, NEW DELHI- 110 108  
TEL.: 23061063, 23061438 (O), 23061924 (F)  
E-mail : dghs@nic.in

दिनांक/Dated:.....

15/04/2019



### MESSAGE

Palliative care is increasingly recognized as an essential part of healthcare system. It is not only confined to pain relief, but includes addressing the physical, psychosocial and emotional sufferings of patients. The increase in the burden of chronic diseases, coupled with increased longevity of the population, has led to increased focus on bringing relief to the sufferings of patients through palliative care.

The National Health Policy 2017 envisions attainment of highest possible level of health and wellbeing for all ages through universal access to good quality healthcare for the population, without subjecting the families into financial hardships. The Ministry of Health and Family Welfare has taken up the initiative of integrating palliative care into the existing healthcare system through the National Programme for Palliative Care and Comprehensive Primary Health Care under Ayushman Bharat.

Human resources with adequate and appropriate training in palliative care are necessary for scaling up palliative care interventions throughout the country. In this endeavour, Community Health Workers play an important role as agents to propagate the health agenda. Therefore, strengthening the capacities of this cadre is paramount.

I commend the efforts of the Program Division in developing this Handbook for Community Health Workers, along with the Facilitators guide for Master Trainers as a good tool for providing these services.

I am sure that this endeavour will go a long way in empowering and encouraging them to take palliative care services, where the need for such services is the maximum.

  
(S. Venkatesh)

**Dr. ALOK MATHUR**

Addl. DDG



सत्यमेव जयते

भारत सरकार  
स्वास्थ्य एवं परिवार कल्याण मंत्रालय  
स्वास्थ्य सेवा महाविशालय  
निर्माण भवन, नई दिल्ली- 110 108  
GOVERNMENT OF INDIA  
MINISTRY OF HEALTH & FAMILY WELFARE  
DIRECTORATE GENERAL OF HEALTH SERVICES  
NIRMAN BHAWAN, NEW DELHI-110 108  
Tel : 23061268  
E-mail : alokmath29@gmail.com

दिनांक / Dated: 15/4/2019

### ACKNOWLEDGMENT

We acknowledge the contributions of the team from National Institute of Health and Family Welfare, New Delhi, comprising of Dr J K Das, Dr Utsuk Datta, Dr Sanjay Gupta, Dr Manish Chaturvedi and Dr Jai Prakash Shivdasani, for their commitment and efforts towards the development of this training manual.

We would also like to acknowledge Dr Alok Mathur from Directorate of Health Services, Ministry of Health and Family Welfare, Dr Fikru Tullu and Dr Atreyi Ganguli from WHO India for their contributions to this manual.

We would also like to acknowledge Dr. Sushma Bhatnagar, Dr Anil Pateri, Dr S Nagesh Simha, Dr Prithwis Bhattacharya, Dr Gayatri Palat, Dr Abhijit Dam, Sister Stella, Dr Savita Butola, Dr Lipika Patra, Ms Harmela Gupta, Dr Ravinder Mohan, for their valuable inputs.

Special thanks to Dr Amit Butola for contributing to the illustrations for the Handbook for Community Health Workers, along with the Facilitators guide for Master Trainers.

(Alok Mathur)

## Abbreviations

- **IAPC** – Indian Association of Palliative Care
- **ISCCM** - Indian Society of Critical Care Medicine
- **ISSP** – Indian Society for Study of Pain
- **MCI** – Medical Council of India
- **MoHFW** – Ministry of Health and Family Welfare
- **NACO** – National AIDS Control Organization
- **NCD** – Noncommunicable Diseases
- **NCI** – Nursing Council of India
- **NDPS Act/Rules** – Narcotics & Psychotropic Substances Act/Rules
- **NGO** – Non-government organization.
- **NLEM** – National List of Essential Medicines
- **NPCDCS** – National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke
- **PC**- Palliative Care
- **RMI** - “Recognized Medical Institution” means a hospital, hospice or other medical institution, recognized by the Controller of Drugs for the purpose of special provisions for use of defined manufactured drugs for medical purpose.
- **WPCA** - Worldwide Palliative Care Alliance
- **WHO** - World Health Organization

## Table of contents

1. Facilitator guide-Introduction to training on palliative care
2. Introduction to palliative care
3. Basic skills required for a community health worker
4. Communication skills
5. Management of symptoms
6. Psychosocial and spiritual support in palliative care
7. Nursing issues
8. End of life care (EOLC)
9. Community participation in palliative care
10. Annexes

## Chapter 1

### Facilitator's Guide-Introduction to training on palliative care

Learning is always best when it is relevant to the needs, understanding, interest and level of comprehension of the learner. Attempt should always be made to keep the learning practical and something the learner is able to relate to.

#### 1.1 Training overview

This facilitator guide provides guidelines for conducting palliative care trainings of community health workers. It will help the facilitators to communicate the information in the training module to the participants using interactive techniques.

Training techniques for community health workers may include:

- Lectures
- Blackboard teaching
- Power point presentations
- Flip charts
- Role playing
- Skits
- Brainstorming sessions
- Problem-solving games
- Small group discussions
- Field visits
- An Internship

The strategy recommended here is that of facilitated learning in groups. The training programme can be carried out over consecutive days or as separate sessions over a period of time. Each chapter indicates the method and time advised but this can vary as different groups may need different ways and time to learn. The facilitator should feel free to add any method which would help teaching eg videos if projector is available and flip-charts/ demonstration with patients where it is not available.

It is helpful to divide the participants into groups of 5–6 members each, to make sure that everyone can take part. All the activities are done in groups and one person from each group reports back to the full team. Others give feedback and comments.

Each session has activities for generate information and knowledge from the participants, followed by sessions by facilitator to sum up, supplement/contest the observations. Sessions for practical skills have hands-on demonstrations by the facilitator. This adds to the information/knowledge/skills available locally. The training contains two segments: a one-day classroom training followed by a one-day Field visit.

The tentative training schedule is as follows:

S.No	Session	Time in minutes
1.	Introduction to palliative care	60
2.	Basic skills required for a community health worker	90
3.	Communication skills	90
4.	Management of symptoms	120
5.	Nursing issues	90
6.	Psychosocial and spiritual support in palliative care	90
7.	End of life care (EOLC)	60
8.	Community participation	120
<b>Total</b>		<b>720</b>

## Chapter 2

### Introduction to palliative care

**Time:** 60 minutes

#### Learning Objectives:

At the end of this session the candidate should be able to understand:

- The meaning and importance of palliative care
- The history of palliative care
- The problems faced by the patient and family
- Who needs palliative care
- The principles of palliative care
- The need for early referral

#### Training methodology

- **Power point presentation/ Blackboard / lecture-** 20 mins
- **Group activity-** 25 minutes
- **Summary-** 15 minutes

#### Group- activity 2.1- 25 minutes

A lady - 35 years old, with a son aged 15 years and two daughters aged 18 and 5 years has just been told that she has advanced cancer of the cervix. Her husband is bed ridden after a spinal cord injury. She works as a cook in two houses to support her family. The doctor has told her brother that the disease is not responding to treatment and she is likely to die in 6–9 months. You visited her yesterday. She has bodyache and pain lower abdomen. She is very worried. What can you do to help her and her family? Who all can you seek help from?

- Discuss in small groups (10 minutes).
- List your suggestions (5 minutes).
- Exchange with other groups (10 minutes).

#### Summary and discussion - 15 minutes

Interactive session- WHO definition, what is palliative care, the need and why it is not available to all the needy.

#### Teaching notes:

##### Introduction to Palliative Care

Palliative care is the total, active care of patients suffering from life limiting illnesses along with care of the family. It relieves suffering and improves the quality of both life and death. 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, psychosocial and spiritual.”*

Palliative care:

- Respects life but also regards death as a normal process
- Does not quicken or postpone death
- Provides relief from pain and other difficult symptoms
- Looks after the psychological and spiritual issues
- Helps the patients live as actively as possible until death
- Helps the family during the patient's illness and after the death

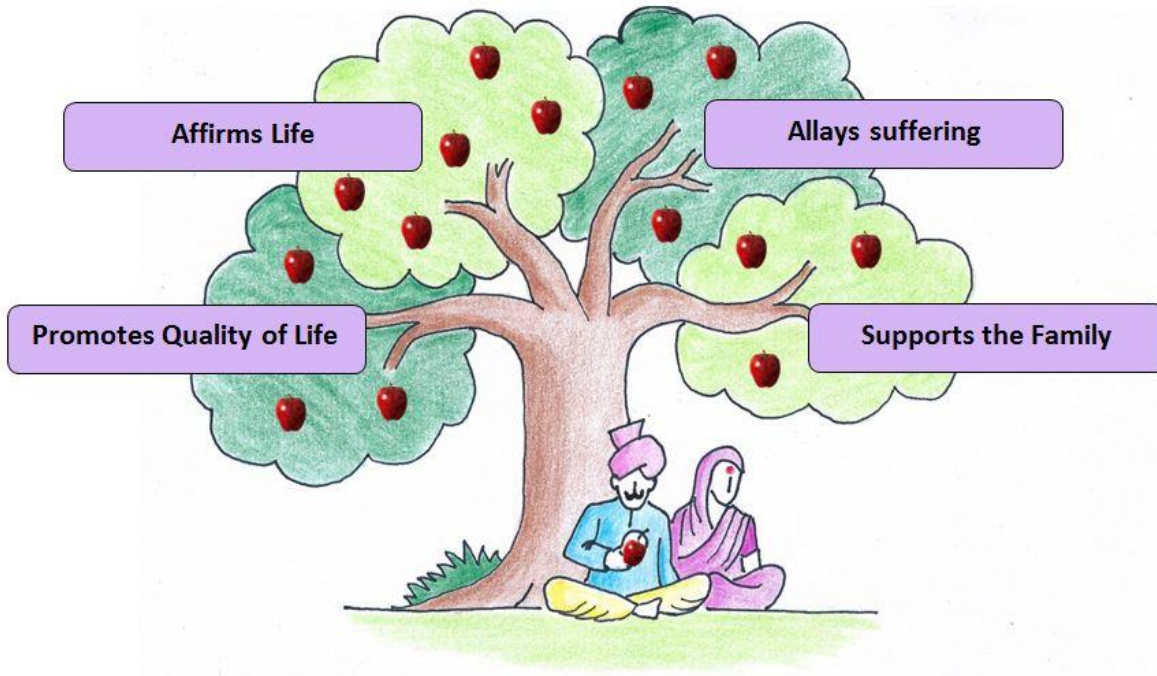
All patients who have incurable diseases need psychosocial and spiritual care along with the routine medical treatment. Palliative care must ideally begin at the time of diagnosis and continue beyond the death of the patient in the form of grief and bereavement support for the family.

### **History**

In the olden days, in India, there were places built where the dying were cared for, like in Varanasi. In the west, the Christian missionaries took care of the old and dying in institutions called 'hospices'. The modern scientific palliative care was started by Dame Cicely Saunders who was a nurse as well as a doctor and a social worker by training. She started the first modern hospice - St Christopher's in London in 1967. From the United Kingdom, the concept spread to other parts of the world and is an important part of healthcare in Australia, Europe and America.

In India, the first pain and palliative care centre started in the Gujarat Cancer and Research Institute at Ahmedabad in 1980 while the first hospice – 'Shanti Avedna Ashram' was started in Bombay in 1986. The first Pain and Palliative care society was started in Calicut in 1992. Most of the palliative care centres are located in Southern India, specially Kerala where community involvement has been the outstanding factor. The 'Indian Association of Palliative Care' was formed in 1994 and is the umbrella organisation which brings together people from diverse backgrounds who are involved in palliative care in India.

## PALLIATIVE CARE



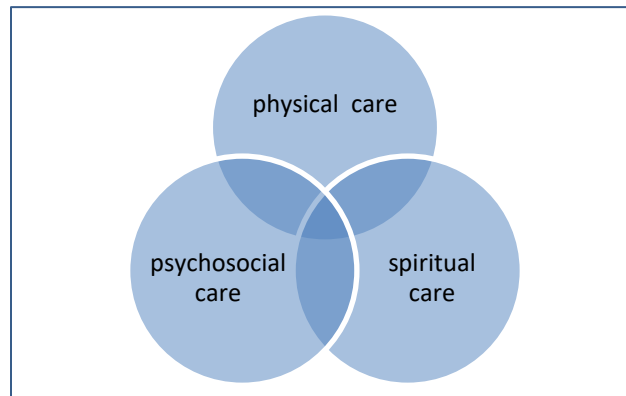
### Who needs palliative care?

Those with:

- Cancer
- HIV/AIDS
- Organ failures like heart failure, lung failure or kidney failure
- Chronic neurological diseases eg- Parkinson's disease
- Stroke or spinal cord injuries
- Old age conditions like Alzheimer's disease
- Children with cerebral palsy or birth defects

### The principles of palliative care

Palliative care looks at the person as a whole to take care of the physical as well as psychological, social and spiritual needs of the patient and the family. When a patient is suffering, the whole family suffers with him. This is the only branch of medicine that treats the patient and family as one unit.



### **The Need**

With changing lifestyle, the non- communicable diseases are becoming more common. They cause 53% of all deaths in India and the maximum number of the patients are in the 35-69-year age group. This is the age when a person is earning, so his illness affects the income of the family too.

Noncommunicable diseases were believed to be diseases of the rich but actually the poor are affected more. The poor have unhealthy living conditions, do not get nutritious food, have more high-risk behaviour, cannot afford medicines and hospitals- all this leads to more psychological and social problems. The maximum need is in the developing countries where two thirds of those needing palliative care live but in these countries enough resources are not available.

These patients and families face many problems- financial, family issues, emotional as well as spiritual. Most people pay for treatment out of their own pocket which pushes millions into poverty every year.

Patients with chronic diseases need not only medical treatment but regular support from their community for all these problems. This is the main difference between acute and chronic patients. Hospitals are meant for care of acute, not chronic illnesses. It is only the community that can support these needs. With change in social structure from joint to nuclear and from rural to urban living, the traditional support systems are no longer available, adding to the difficulty.

Palliative care requires a team with many people as no single speciality can meet all these needs. It require various specialists like oncologists, orthopaedicians, paediatricians working alongwith palliative care physicians, nurses, medical social workers, spiritual care guides, community health workers, physiotherapists as well as the patient's family to provide good quality of life to the patient.

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% are able to 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 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?”.

### **Where can palliative care be given?**

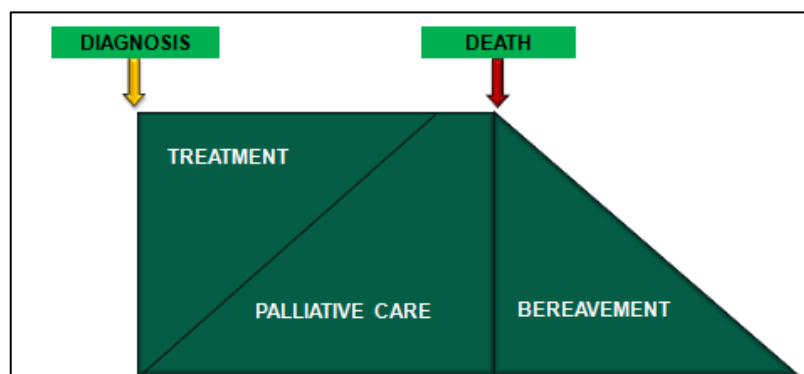
Palliative care can be given anywhere - at home, in the hospital or in a place for the terminally sick which is called a ‘hospice’. In India, homecare is considered better because most of the patients are more comfortable in their own home. It is not only cheaper but also allows the family to take care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

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 into existing healthcare 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 and can be provided by training doctors and nurses 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.

### **Early palliative care gives the best results**

Palliative care should be started early in the disease to be really helpful. Early involvement of the palliative care team helps build trust with the patient and family, plan ahead well in time to prevent symptoms rather than trying to control them when they become too much. It also helps have timely discussions with the family about withholding treatment which is not helpful. It helps plan for good end of life care by making wise, well-informed and timely decisions when the disease becomes progressive. Sadly, most patients are sent for palliative care when it is too late to be of much use. One important reason is that most people don’t know about palliative care or think of it as only terminal care for the dying. Terminal care is an important part of palliative care but palliative care is much more than just end of life care.

The diagram below shows that ideally, palliative care must start at the time of diagnosis along with curative treatment. Early in the disease, the curative treatment is more and the palliative treatment is less. As the disease progresses, the curative part becomes less and the palliative part becomes more. When patient is nearing the terminal phase, it takes the form of ‘end of life care’. After the death of the patient, it continues in the form of grief and bereavement support for the family.



The Government of India launched the 'National Programme for Palliative Care' in 2012 and is training doctors, nurses as well as ASHA workers in all the states so that patients in even the remote areas can be identified and cared for. ASHA workers can be helpful in:

- Identification of patients
- Referring for palliative care
- Guiding families for nursing care at home
- Acting as a link between the patient, the family and the palliative team
- Help create awareness and change the wrong beliefs about diseases like cancer or HIV
- Create awareness about various benefits and welfare schemes provided by the government.

### Important Messages

- **Definition-** *'Palliative Care is 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, psychosocial and spiritual.'*
- Palliative care is needed by those with:
  - Cancer
  - HIV/AIDS
  - Organ failures like heart failure, lung failure or kidney failure
  - Chronic neurological diseases eg- Parkinson's disease
  - Stroke or spinal cord injuries
  - Old age conditions like Alzheimer's disease
  - Children with cerebral palsy or birth defects
- Over 5 million Indians need palliative care each year but less than 1% get access to palliative care.
- Palliative care looks after the physical, psychological, social and spiritual needs of the patient and the family.
- It can be given in a hospital, a hospice or at home. In India, homecare is believed to be better as it is more economical and culturally acceptable.
- Most of the palliative care needs can be met at the primary level and in the community.
- It should be an integral part of healthcare at all levels- primary, secondary and tertiary.
- Patients should get palliative care right from the time of diagnosis along with other treatment. Early integration gives the best results.
- It takes care of person as a whole, rather than focussing on the disease.
- End of life care is an important part of palliative care but palliative care is much more than terminal care.
- The 'National Programme for Palliative Care' was launched in 2012 and provides for training of medical staff in all districts in the country.

### Self-assessment questions

1. Define palliative care.
2. Who are the patients you would advise palliative care for?
3. What are the problems faced by patients with incurable illnesses?
4. How is early palliative care helpful?
5. Why homecare is considered better strategy for long term care?

## Chapter 3

### Basic skills required for a community health worker

**Time:** 90 minutes

#### Learning Objectives:

At the end of this session the candidate should be able to understand the basic skills required for fulfilling the role as a community health worker.

#### Training methodology:

- **Power point presentation / Blackboard/ lecture** - 10 minutes
- **Group activities-** 75 minutes
- **Summary-** 5 mins

#### Instruction to the facilitator:

The candidates can be divided into groups of 4-6 persons. Every group should elect a group facilitator whose responsibility will be to conduct the discussions and a reporter who will be reporting the group's suggestions and opinions to the larger group during feedback. After each group discusses the questions below, gather the feedback and write them on a back/white board or on a flipchart for everyone to see. Finally the facilitator to make a short presentation based on the reading material below.

#### Group activity 3.1 – 15 minutes (in separate groups)

**Discuss** the role and responsibility of ASHA in community palliative care.

- List the all the activities that a CHW will do while visiting an ageing bedridden lady at her home
- What are the skills required by the CHW for effectively undertaking these activities?

#### Carers' responsibilities to patients

- **Confidentiality**

You are looking after a 40 -year-old woman with HIV. The patient's family loves and respects you. During one of your visits, the patient tells you about a relationship she had with another man. She has not revealed to anyone else before. She says he feels guilty about it. When you are about to leave, the patient's husband asks you what you were talking about. He is curious as the patient was crying. What will you tell him?

- **Discussion in groups** – 5 minutes
- **Reporting** - 5 minutes
- **Summarize** -5 minutes

**Confidentiality** is a must for the patient to share personal information. Patients must be able to trust the carer. Only then can a patient share the private feelings and personal history so that we can get a complete picture and decide on the action needed. Confidentiality is not only an ethical issue but also a legal requirement. Always remember that a carer is entrusted with this information only to help that patient.

- **Ethical principles** while looking after patients
- **Autonomy:** The patient has the right to decide what he or she wants
- **Non-maleficence:** Do not harm the patient
- **Beneficence:** Do good to the patient
- **Justice:** Principle of fairness and equality. Use resources sensibly so that maximum people can get benefit.

### Activity 3.2 – 30 minutes (all groups together)

One person from each group reports and the facilitator writes all the points in a board or flipchart.

A patient 62 year old, just retired school teacher has advanced liver failure and jaundice. The doctors at two government medical colleges have told the family that he is dying. They advised the family to take him home and look after him. He is semi-conscious and unable to eat or drink. The wife is not able to eat anything since he is not eating and she has never eaten before him. He has four sons and they all want to take him to be admitted to a big private hospital and want 'everything done'.

Based on the ethical principles mentioned, discuss the dos and don'ts while caring for such a patient. Encourage sharing of experiences

- **Discussion-** 10 minutes
- **Reporting-** 10 minutes
- **Summary** - 10 minutes

### Activity 3.3- 30 minutes (all groups together)

The facilitator makes a short presentation on the topic; ensuring that the points discussed below are covered.

#### Discussion in groups

- Do you think that the patient should know the diagnosis and prognosis? Why?
- Do you think that you should be told the diagnosis if you are diagnosed to have a major disease? Why?
- Do you think your family member and not you should be told the diagnosis? Why?

**Discussion** - 15 minutes

**Reporting** - 15 minutes

## Teaching notes:

### Introduction

The challenges the chronically, incurably ill and bed ridden persons in our communities face involve all their domains of life and ranges from issues of day to day living to health care. They will be emotionally upset, socially isolated due to their disabilities or indifferent societal attitudes, become heavily dependent on others for their care and survival and are often turned away from health care institutions because these institutions feel that 'there is nothing much they can do to make him/her better'. The patients, their carers, the communities and the health institutions feel helpless when faced with conditions requiring long term care and palliative care.

It has been established that such patients can receive good quality comprehensive care at their localities and homes through provision of palliative and long-term care at primary health care level and home care. Such comprehensive care cannot be achieved by the health institutions alone but also needs the support of the communities these patients and their carers live in and interact with. There will be physical issues arising out of the disease and debility they are suffering from but most problems faced by people living with advanced and incurable conditions, including ageing, are social, emotional and spiritual. These issues cannot be addressed without the support and intervention by the communities.

The Community Health Care Worker (CHW) will be the most important person in linking up the patient, community and health institutions. They should be adequately prepared to take up this challenging yet satisfying responsibility. To address the physical issues of the bedridden patients one should possess good nursing knowledge and skills, which are discussed elsewhere in this book. This chapter is on the basic skills a CHW should have to fulfil their roles.

A CHW should demonstrate in his/her work compassion, empathy, honesty, tolerance, discipline, common sense, adequate technical skills, confidence, credibility, dignity, self-control, sense of humour where appropriate, generosity and composure.

### The aims of care are to

- Reduce or stop pain and suffering
- Cure the condition whenever it is possible
- Help to regain and sustain health
- Early identification and prevention of diseases

### The basic principles to applied while caring are to ensure

- **Safety** of the patient and the carer
- **Effectiveness** of the interventions
- **Comfort**, both physical and psychological
- **Fair use of resources**
- Adequate **knowledge and necessary skills** for self
- **Individualisation** of the interventions and treatment

In the following sections the skills required by the CHW to be effective in their role are discussed

## Communication skills

- **Active Listening:** This is one of the basic skills required for a Community Health Worker (CHW). Active Listening is different from hearing. Understanding what is being said by patients, families, colleagues and others is important. If we are not able to understand the content, we should ask appropriate questions to get it clarified and should not assume things.
- **Speak:** CHW should be able to speak clearly so that the information is effectively conveyed to the listeners.
- **Read and write:** CHW should have the basic reading skills to understand the written information and should be able to write clearly so that others can understand the information.

## Assessment and intervention skills

**Assessment:** The CHW should have the necessary knowledge and skills to identify the right persons who can benefit from the service. A screening tool is annexed which can be used for initial survey/screening of the community to identify potential beneficiaries from palliative care. Apart from assessing the primary care needs of the patients and family, the CHW should be able to explore and recognize the physical, social, emotional and other issues which can impact patients' wellbeing. A format for the initial detailed assessment of the patient annexed. This may include discussing with colleagues or seeking the opinion of an expert in the team before finalizing the management plans.

**Interventions:** The CHW should have good judgment and decision-making skills to decide, based on the assessment and consultations, what will be the possible interventions at their level, their risks and benefits and effectively communicate these to the concerned persons. They should help the patient and family to take appropriate decisions and guide them through to implement those decisions effectively.

The patient, and, where relevant, the family as well, should be actively supported and guided through the decision making processes on issues pertaining to their health by providing appropriate information. The CHW should maintain strict confidentiality with regard to the information they gather about the patient and family. These are to be discussed only with relevant people of the care team and should not lead to compromising patient's privacy and dignity.

**Referrals / Networking:** The CHW should know when to refer a patient and also know the resources / facilities available in the community / region which can be made use of for the benefit of patients and families. Example would be referring the patient to a higher centre for better care or getting the supply of patient care equipments or social support from a NGO in the area.

## Working with the community

**Understanding social dynamics:** The CHW should be well connected to the community they are serving and able to understand its social dynamics. This help them in turn to understand the behaviours and reactions by people and respond in a better way to them. CHW should be actively looking for solutions to the problems and innovative ways to help the needy.

**Sensitivity to cultural issues:** They should be sensitive to the cultural issues in the society and sensibly work with different cultural contexts.

***Don't push own agenda:*** The CHW should not let their political, religious or cultural beliefs and views influence their decision-making processes and care provision. They should not take advantage of the helplessness of the patients and families to push their own agenda.

## **Capacity building**

***Educating others:*** CHW should have the basic teaching skills to effectively instruct patients and families in health related issues. This may include using the available information materials and making presentations at appropriate forums.

***Educating self:*** There should be a constant effort by the CHW to improve own knowledge and skill. This will lead to better care provision and also reduce the stress at work place.

## **Special skills**

***Organizational and leadership skills:*** The CHW should be able to lead the programme effectively, be a role model to others, to have vision for the future of the programme, mobilise resources and people from the community to support the programme. Credibility is a key factor in assessing their role by the community.

***Management skills:*** The CHW should be able to organise the care programme at their level. This may include time management, preparing schedules, procuring supplies, taking inventories, documenting, preparing reports, communicating relevant information and financial transactions where appropriate.

***Documentation:*** CHW should know how to document the problems/ interventions in the target population

***Advocacy skills:*** The CHW should act as an advocate for the cause of palliative care and the persons supported by them and raise their issues in relevant forums.

***Evaluations skills:*** The CHW should evaluate their services periodically and take part in surveys and data collections for relevant projects.

### Important messages

Based on the points discussed above, the possible steps the CHW can follow while visiting people at home are given below.

- Know the patient and family well. Even if you know them cross check beforehand the names, conditions he/she is suffering from, socio-cultural status. If you are on a follow-up visit check the problems he/she had had and the interventions planned and if there is anything that the care team had to take note of.
- Address patient and family in a respectful way. Introduce yourself and the team members. Explain the purpose of the visit. Try to strike up a friendly conversation.
- Explore the issues. You may start from the most distressing issue and move on to the others. If situation demands filling up the demographic data can be done later during the visit.
- Listen actively (Please see the section on communication to learn more about active listening). Explore relevant issues beyond physical domain such as social, emotional, financial, spiritual. Patient and family may not share all their feelings on the very first visit itself and they may do so during the subsequent visits. If they do not want or are uncomfortable discussing a certain issue do not force them to and you can come back to such issues later when a good rapport is built. Allow them to ask questions. If you are not very sure about the answers tell them so and may discuss with relevant 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 interventions done. An abridged version of the initial assessment format which can be used for documenting the follow up visits to the patient is annexed.
- Plan further follow-up if required and date for next visit. Communicate this to the patient and family.

### Self-assessment questions

1. How can you build your communication skills?
2. How can you facilitate networking and referrals in the community?
3. What are the key messages you will deliver during your home visit?
4. How can you motivate the community on their participation for palliative care?
5. What are the possible options for building your capacity and knowledge enhancement?

## Chapter 4

### Communication skills

**Time:** 90 minutes

#### **Learning Objectives:**

At the end of this session, the candidate should be able to:

- Understand the fundamentals of communication and know how to communicate with the patients.
- Develop good listening skills
- Appreciate the difference between good and poor communication.

#### **Training Methodology:**

- Interactive session
- Role play

#### **Activity 4.1-** 5 minutes

##### **Introduction**

Ask one person in the group to narrate an experience in which a communication process went wrong (did not have the intended result or had the opposite result) and her thoughts now on why this happened.

#### **Activity 4.2 –** 5 minutes

Ask the group for a few examples of non-verbal communication

#### **Activity 4.3 –** 20 minutes

##### **In groups, discuss the following:**

- Are there any preparations needed when we visit a patient?
- What do you talk about with the patient?
- What are the dos and don'ts in such a conversation?
- How do you conclude the conversation and take leave?

**Discussion** in groups- 10 minutes

**Reporting-** 5 minutes

**Summary-** 5 minutes

#### Activity 4.4- 20 minutes

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

**Discuss** in groups:

- Difficulties in communication with patients: The difficulties can be due to individual factors (patient or carer) or social factors.
- Discuss your difficulties
- Generally, what are the barriers to proper communication with patients?

**Discussion** - 10 minutes.

**Reporting** - 5 minutes

**Summary** of barriers to communication - 5 minutes

#### Activity 4.5 - 20 minutes

##### **Active listening**

**Group work:** Discuss: -

**Attributes of good listener:** How do you want the listener to listen when you talk to him/her?

*(Discussions in groups, followed by reporting)*

##### **Group Work:**

Attributes of good speaker: How do you want the speaker to speak when he/ she talks to you?

*(Discussions in groups, followed by reporting)*

**or**

Group exercises to be carried out in pairs with an attentive listener versus an inattentive listener. A feedback is to be collected on what the speaker felt.

**Group work-** 10 minutes

**Reporting-** 5 minutes

**Summary** and discussion - Active Listening – 5 minutes

#### Activity 4.6-- 20 minutes

##### **Role Play**

**Explain** - 5 minutes

**Role Play-** 10 minutes

**Discussions-** 5 minutes

Let the participants play the roles of a patient, a family member and a health worker. Play out scenarios of rude talk, staff not paying attention or language barriers with misunderstandings.

Get feedback and discuss what could have been better- 5 minutes

### **Teaching notes:**

#### **Introduction**

Communication is exchange of ideas or feelings between two or more people on a common background or agenda. Communication is important with the patient and family for proper assessment of their problems and intervention. It is the quality of communication that makes the difference. This can relieve the patients and families psychosocial problems. Communication can be verbal or non-verbal. Knowingly or unknowingly, patients and families grasp non-verbal communication more than verbal communication. The process of communication is complex and more than 70% of communication takes places through non-verbal means.

#### **Why do we communicate?**

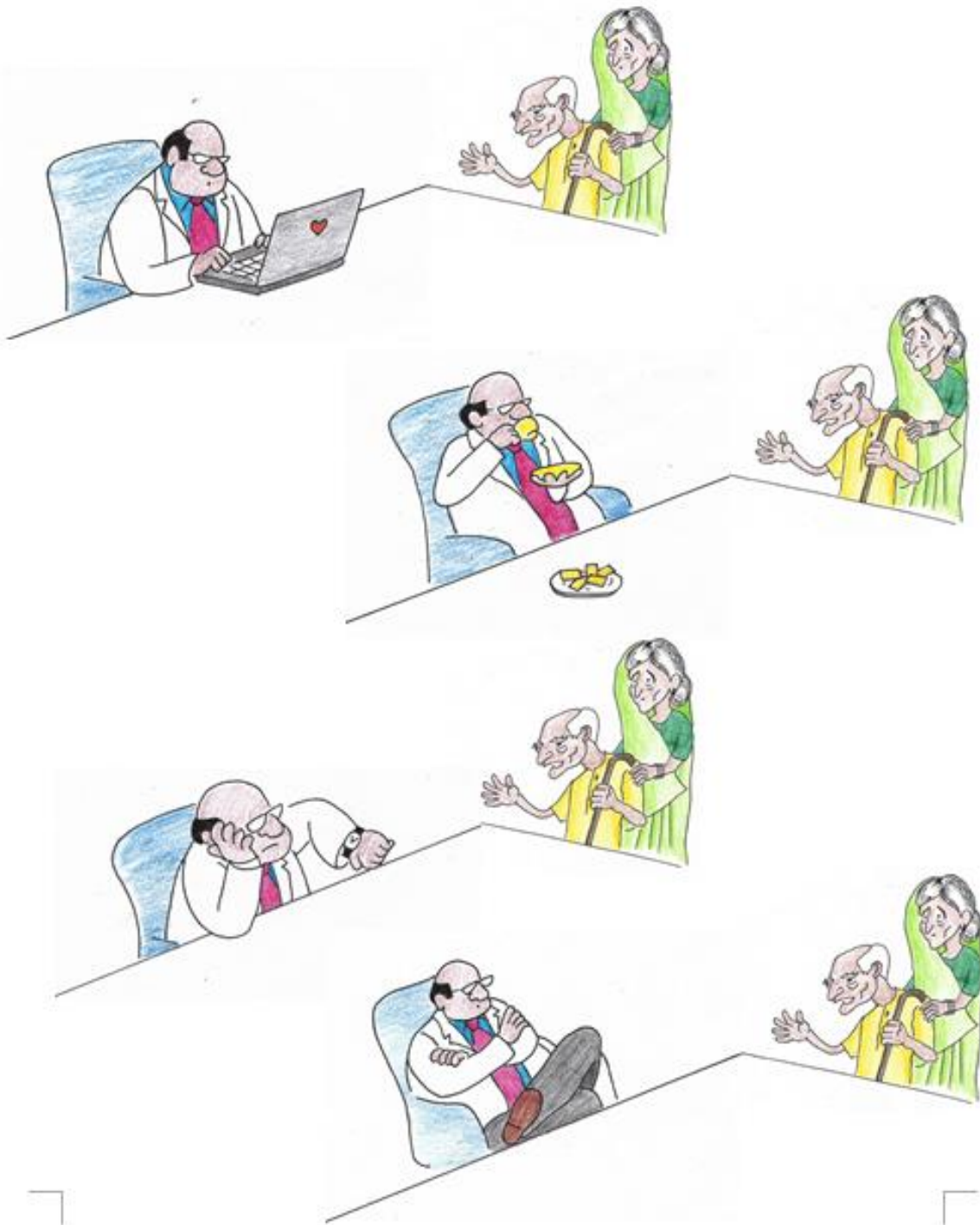
- To convey information or ideas
- To deepen our understanding of issues
- To gain acceptance and trust
- To build a good relationship with the patient and family.

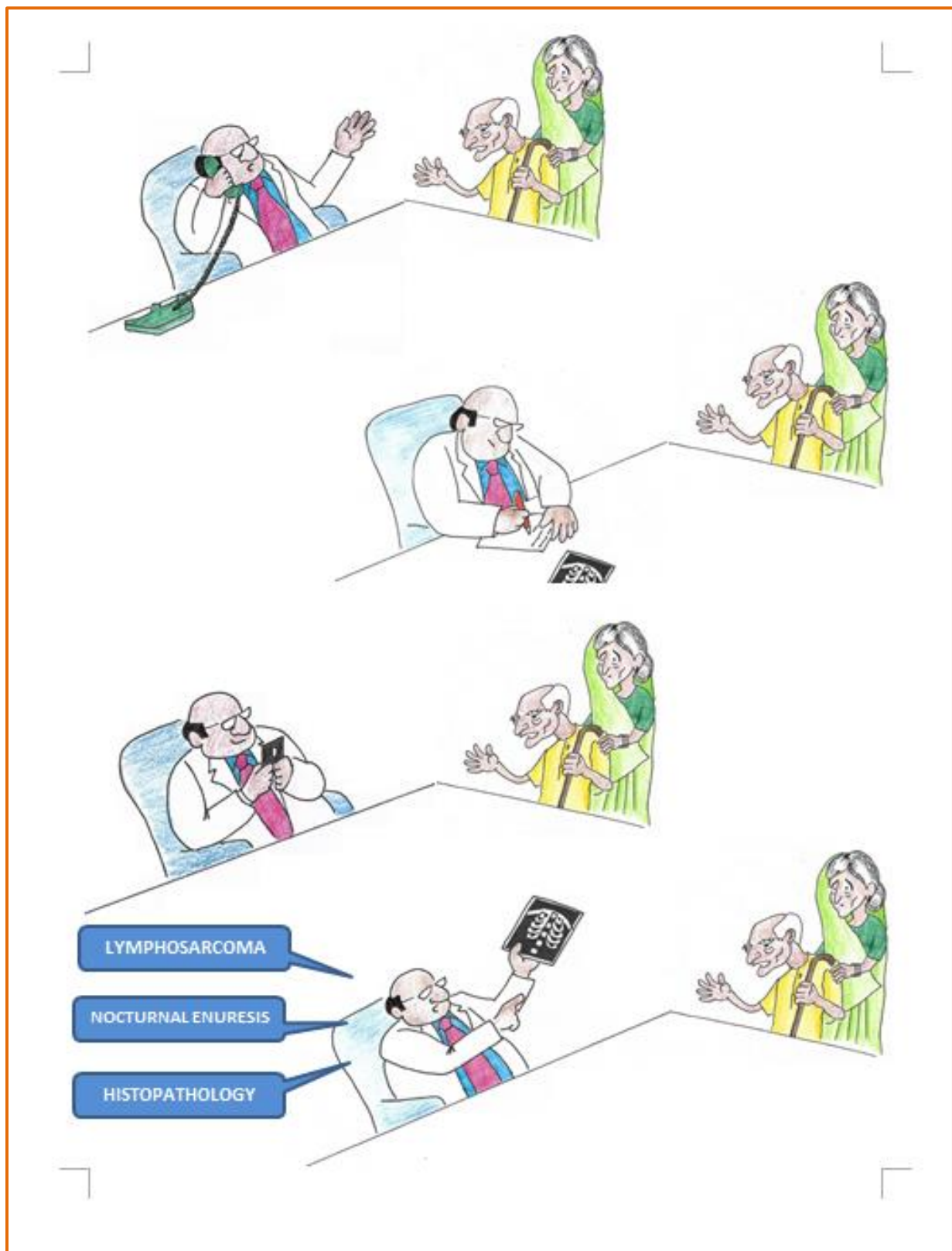
#### **Aims of effective communication between ASHA workers and patient**

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

This process is a two-way conversation between the ASHA worker and patient /family and not a one- way communication.

## BARRIERS TO COMMUNICATION





### **Consequences of poor communication**

- Distrust
- Poor symptom control due to unrealistic expectations
- Depriving the patient of the opportunity to address unfinished business
- Increased patient distress and anger
- Lack of co-operation and increasing demands from the patient
- Isolation from family and society.

### **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”
- Unable to handle patient’s emotions
- Unable to improve the situation.
- Fear of being blamed
- Language is a problem.
- Busy schedule.

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

- We are busy (we pretend to be busy)
- Interested to know about their physical issues.
- Not enquiring about their emotional problems, in case they complaint afraid of denying the treatment.
- Cannot control their emotions like crying, what the HCP will think about him/her.
- Do not have the courage to hear about the truth.
- Language is a problem.
- Cannot follow the medical terms.

### **Problem arising in communication:**

- Distancing behaviors
- Pretending to be busy
- Failing to explore beyond physical issues
- Premature/false reassurance
- Inappropriately introducing humor
- Concentrating on Physical issues.
- Disappearing from the stressful situation
- Patronizing and talking down to patients
- Using medical terms.

## **Basics steps of communication**

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

## **Preparing for listening**

- Introduction
- 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 - encourage the patients to talk about the problems.
- Closed questions – need to ask the patient further questions regarding their problems.
- Leading questions – not to ask the patients.
- Biased questions (disguised statements) – not to ask the patients.

## **Effective listening and facilitating:**

1. Stop Talking
2. Encourage the patient to talk.
3. Show that you want to listen, maintain eye contact
4. Remove distractions
5. Empathize with the patient.
6. Be patient, tolerate short silences
7. Hold your temper
8. Don't argue or criticize
9. Ask questions
10. Do not interrupt unnecessarily.
11. Acknowledge patients/families emotions.

## **Responding -Hearing (showing that you have heard}**

- Summarize whatever the patient/family told you.
- Prioritize the problems from the patient's side.

**General Points to remember**

1. You have information about the patient which patient doesn't have.
2. Patient satisfaction does not depend on the time spent.
3. All questions may not have answers.
4. More important questions may be enquired with the other health care providers or link them with the nearest primary health centers.

**Basic three principles**

1. Genuine – do not lie to the patient.
2. Positive regard to the patient
3. Empathy.

**How to start the conversation?**

1. Ask the patient how he/she came, who has come with him / her.
2. What brings them here?
3. Is she/he comfortable?
4. Provide privacy
5. In person or with a relative
6. Listen to the words or phrases that the patient uses
7. Note the emotional tone when patient communicates (Non verbal & verbal)
8. Find out about the patients issues.
9. Willingness to know about the treatment
10. Discuss with the patient what the patient wants to know.

**Points to remember:**

- Talk in simple language
- Speak clearly, and 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 whether the patient and family understand the problem.
- Never patronize with the patients
- Listen to patient's ideas and unanswered questions
- Try your best to align your ideas with those of the patient's.

**Planning and follow-up:**

- Understand patient's list of problem.
- Make a care plan about how to manage the problems.
- Explain the plan of management.
- Prepare for the worst while hoping for the best.
- Help identify individual coping strategy
- Identify other support sources and incorporate them in summary report
- Summarize and open the door for future contact

**Barriers in communication:**

- Pretending to be busy.

- Concentrating on easy jobs.
- False reassurance and inappropriate humor.
- Comparison.
- Being judgmental.
- Showing sympathy.
- Medical jargon.

#### **Important Messages**

- Communication is an art that has to be developed or will develop with experience. Each patient is an individual, so never compare with another.
- Identify our skills and try to refine them.
- Identify our shortcomings and try to overcome them.
- There are no fixed guidelines.
- Should be patient centered and context oriented.
- Never try to imitate others.

#### **Self-assessment questions:**

1. What is communication?
2. What is the need of communication?
3. What are the difficulties in communication?
4. Points to remember in effective communication?

## Chapter 5

### Management of symptoms

**Time:** 120 minutes

#### Learning objectives

At the end of the chapter, the candidate should be able to:

- Define, assess and manage pain in patients with palliative care
- Understand WHO Pain Relief Ladder
- Acquire an understanding on breathlessness in patients receiving palliative care, use of oxygen and nonpharmacological management of breathlessness
- Manage common gastrointestinal tract, respiratory and urinary symptoms in patients with palliative care

#### 5.1: Pain Management

##### Training Methodology:

**Power point presentation / Blackboard/ lecture –10 minutes**

**Activity 5.1-** 30 minutes

**Discuss experience with patients who have pain**

**Do you think they are adequately relieved?**

**Do you think family and health care workers are sensitive to patient's pain and suffering?**

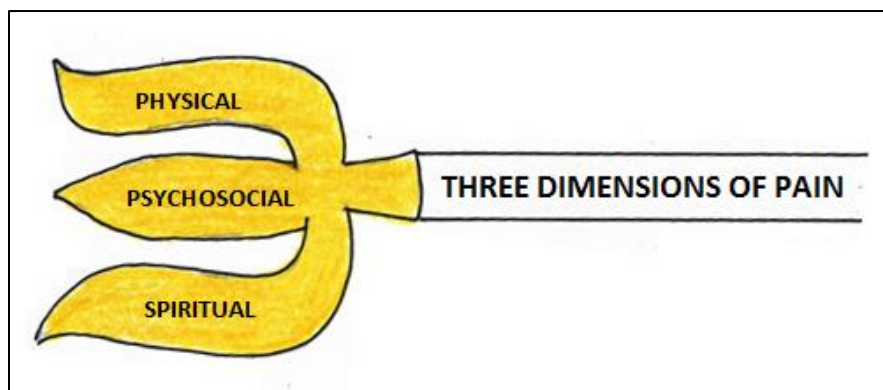
**Discussion – 10 minutes**

**Reporting -10 minutes**

**Summary- 10 minutes**

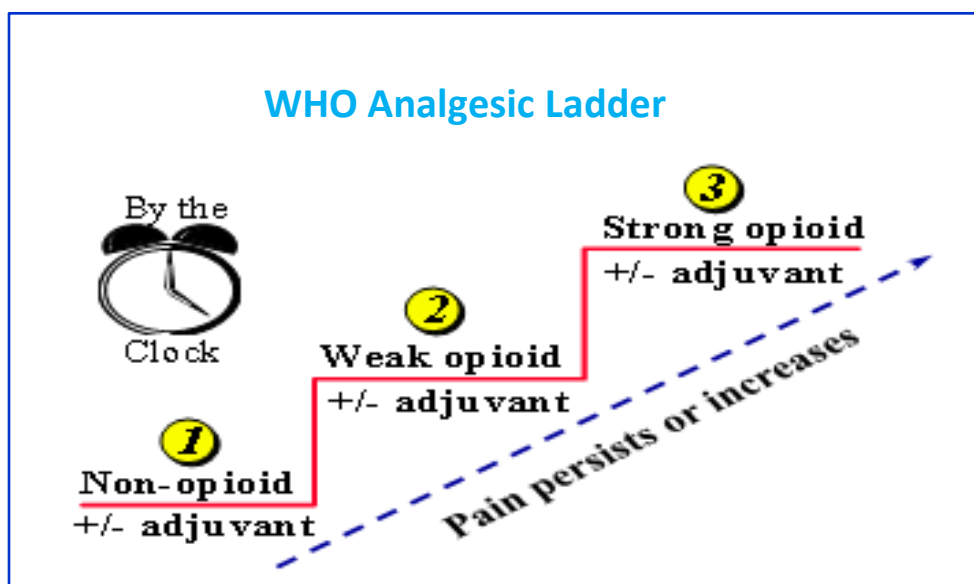
##### Teaching notes:

**Definition of Pain:** "Pain is an unpleasant, subjective, sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." The experience is subjective and would be perceived differently by each person. The term **"Total Pain"** is used when psycho social, physical, and spiritual distress, combine to affect the patient.



When prescribing for continuous pain, remember:

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



**Note:** Once the patient is started on the analgesic ladder it is very important that they are 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,

#### Basics of Morphine:

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

**Myths about Morphine:**

- Only for patients with cancer
- Only when end of life is near
- Addiction/dependence
- Respiratory depression
- Can't be used for children

**Morphine Side Effects:**

- Constipation - need proactive laxative use
- Nausea/vomiting - metoclopramide, domperidone, haloperidol
- Urinary retention
- Itch/rash - May try antihistamines, however not great success
- Dry mouth
- Respiratory depression – uncommon when titrated in response to symptom
- Neurotoxicity - delirium, myoclonic jerks

**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

**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.

**Non-pharmacological interventions**

A range of techniques exists to complement the pharmacological approaches. Not all approaches will be appropriate for every patient. Positioning, reassurance, good communication, psychological support, joint mobility (passive & active), spiritual counseling, diversion therapy, art or music therapy, etc. are also useful.

**5.2: Breathlessness** - 20 minutes**Teaching methodology****Power point presentation / Blackboard/ lecture** – 10 minutes

**Discuss** the reasons for the patient not taking medicines as prescribed (elicit comments from the group).

**Discussion-** 5 minutes

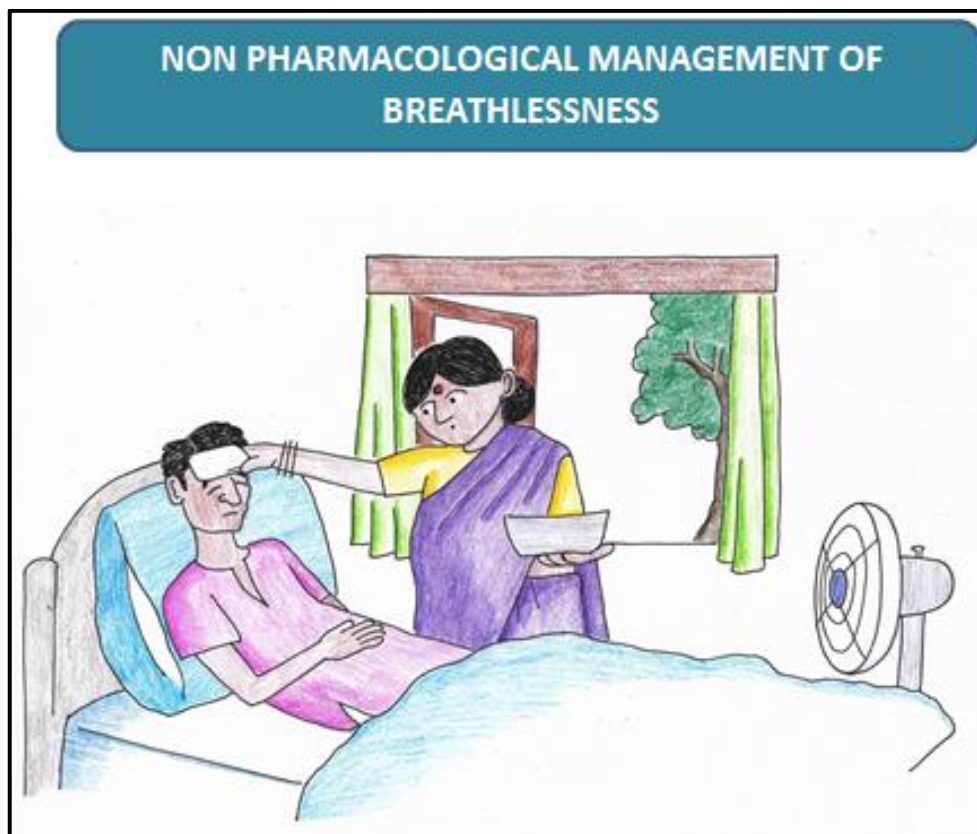
**Reporting-** 5 minutes

### Teaching notes:

Breathlessness restricts activities and results in loss of independence, frustration, anger and depression. Breathlessness at rest can induce severe anxiety leading to panic attacks. It occurs in 50% of patients referred for palliative care. Patients often fear suffocating to death. A positive approach to the patient and their family about the relief of the breathlessness is therefore important.

### Management:

1. Look for reversible causes of breathlessness.
2. Drugs are commonly used to reduce the bronchospasm, to relieve anxiety and to be used round the clock as advised by the doctor. Morphine reduces inappropriate and excessive respiratory drive and substantially reduces the ventilatory response to hypoxia (low Oxygen) and hypercapnia (increased CO<sub>2</sub>).
3. Oxygen: is often only helpful if there is hypoxia and cyanosis.
4. **Non-pharmacological treatment:** Relaxation techniques, physiotherapy in the form of breathing exercises etc. May be very helpful. Directing a stream of air over the face can reduce the sensation of breathlessness. Managing breathlessness at home is particularly challenging and carers need to be taught how best to support the patient. Simple measures include ensuring good ventilation, use of a fan to encourage a flow of air across the face, calm environment, avoid tight clothes, keeping mouth moist.



### **Terminal breathlessness**

Patients often fear suffocating to death. A positive approach to the patient and their family about the relief of the terminal breathlessness is therefore important. No Patient should die with distressing breathlessness. Call or refer to doctor for symptom relief.

### **5.3: Nausea and vomiting**- 20 minutes

#### **Teaching methodology**

**Power point presentation / Blackboard/ lecture** – 10 minutes

**Discuss** the reasons for the patient not taking medicines as prescribed (elicit comments from the group).

**Discussion**- 5 minutes

**Reporting**- 5 minutes

#### **Teaching notes:**

“Nausea is an unpleasant feeling of the need to vomit” and “Vomiting is the forceful expulsion of gastric contents through the mouth”. Nausea and vomiting are the symptoms which can cause patients and their relatives in deep distress. Of the two, nausea causes most misery.

### **Management**

#### **Non-pharmacological management:**

- Control of malodour from fungating wound, ulcer, colostomy etc.
- A calm, reassuring environment away from the sight and smell of food
- Avoid exposure to foods, which precipitate nausea
- Small frequent meals

#### **Pharmacological management**

Always give anti-emetics regularly, not as SOS. If vomiting is continuous, try to avoid oral medications and then consult the doctor.

**Opioid - induced nausea and vomiting**-It is worth considering reducing the opioid dose. If nausea and vomiting are distressing, consider reducing the dose or another opioid. Consult doctor

### **5.4: Constipation**- 20 minutes

#### **Teaching methodology**

**Power point presentation / Blackboard/ lecture** – 10 minutes

**Discuss** the reasons for the patient not taking medicines as prescribed (elicit comments from the group).

**Discussion**- 5 minutes

**Reporting**- 5 minutes

### Teaching notes:

Constipation is characterized by difficult or painful defecation and is associated with infrequent bowel evacuations and hard faeces. Constipation remains as an underestimated symptom which severely affects the sense of well-being of the patient. So a good history is required to resolve the symptom. About 45% of patients are constipated in the palliative care setting. Complications of constipation include a general feeling of bloating and rectal fullness, loss of appetite, abdominal pain, bowel obstruction, overflow diarrhoea and urinary retention.

### Causes:

- Immobility leading to decreased peristalsis
- Decreased food intake and low fiber diet
- Poor fluid intake or increased fluid loss (vomiting, diarrhoea)
- Inability to raise intra-abdominal pressure (general debility, paraplegia)
- Inability to reach toilet when urge to defecate occurs
- Opioids (90% of patients taking opioids need laxatives)
- Embarrassment in public setting
- Pain on defecation (fissure in ano)

### Management

#### Non-pharmacological management of constipation

- Access and ability to get to the toilet may be more important than a supply of laxatives
- Timing and privacy
- Straining compromises defecation and damages pelvic floor function
- A squatting position facilitates efficient funneling of the pelvic floor, favoring defecation
- As far as possible patients should be encouraged to eat a normal balanced diet and drink plenty of fluid.

**Pharmacological management of constipation for more severe constipation and faecal impaction- Consult Doctor**

### 5.5: Diarrhoea- 20 minutes

#### Teaching methodology

**Power point presentation / Blackboard/ lecture – 10 minutes**

**Discuss** the reasons for the patient not taking medicines as prescribed (elicit comments from the group).

**Discussion-** 5 minutes

**Reporting-** 5 minutes

### Teaching notes:

Diarrhoea is the passage of frequent loose stools. It has been defined as the passage of more than three unformed stools within a 24-hour period. As with constipation, patients can understand “diarrhoea” in different ways and clarification of the term is always required. Diarrhoea is less

common than constipation in patients requiring palliative care. Up to 10% of patients with palliative care needs complain of diarrhoea.

#### **The common causes of diarrhoea in the palliative care setting:**

- **Imbalance** of laxative therapy - commonest cause.
- **Drugs** (antibiotics, pain medications)
- **Faecal impaction** may be associated with fluid stool which leaks past a faecal plug or a tumor mass ("overflow diarrhoea")
- **Bowel fistulae**
- **Odd dietary habits**

#### **General Measures**

- Increase fluid intake, frequent sipping of water.
- Reassurance that most diarrhoea is self-limiting.

#### **Specific drug treatment - consult a doctor**

#### **Further reading**

1. Twycross, R., Wilcock, A. and Toller, C.S. (2009) Symptom Management in Advanced Cancer. 4th edition. Palliativedrugs.com Ltd., Nottingham.
2. World Health Organisation (1996) Cancer Pain Relief. WHO, Geneva.
3. Dickman, A. Drugs in Palliative Care (2010) Oxford University Press, Oxford.
4. Back, I.N. (1997) Palliative Medicine Handbook. Marie Curie Cancer Care, Penarth.
5. Palliative pain and symptom management pocket reference guide: Palliative Care Experts in the Erie St. Clair and South West LHINs (<http://www.market-marche.chpca.net/>)

#### **Important messages**

- Basic knowledge of symptom control improves quality of life of the patient and makes the family and the team more confident to deal with the situation
- Both drug and non-drug management have important role in symptom control

#### **Self-assessment questions**

- What do you mean by the concept of "Total pain"?
- What advice will you give to the patient regarding pain medicine?
- What are the non-drug management of breathlessness?
- Define Nausea and vomiting and mention its causes?
- What are the common causes and complications of constipation?
- Mention non-drug management of constipation?

## Chapter 6

### Nursing issues in palliative care

**Time-** 90 mins

#### **Learning Objectives:**

At the end of this session, the candidate should be able to:

- Understand the importance of the care of bedridden patients and demonstrate the care step by step.
- Identify the problems of bedridden patients
- Educate the family about the care of the patient.
- Demonstrate the care to the family.

#### **Training methodology**

- Interactive sessions with hands on demonstrations
- Videos

**Handwashing**

**Mouth care**

**Bed care- changing sheets, filling up water bed**

**Bed bath**

**Perineal care**

**Catheter care-**

**Demonstrate** catheter (Foleys and Condom) and urobag

**Demonstrate** how to empty urobags

**Preparing dressing material at home**

**Wound dressing**

**Lymphedema care**

- Massage
- Bandage

**Bed Sore care**

**Disposal of waste**

**Moving the patient**

## Teaching notes:

### Care of bed ridden patient

Nursing care of bed ridden patients is quite challenging for nurses. Patient may be conscious or unconscious. A patient becomes bedridden due to a disease or aging. In both the cases, a patient needs total care

In an unconscious bedridden patient the following care is important:

- Health education of the family in care of the patient.
- Involve the family in all the care.
- Demonstrate the care and make a follow up.
- Regular home visits.
- Documentation-, recording and reporting.
- Airway clearance
- Adequate fluid intake (Nasogastric tube feeding)
- Bowel and bladder care because of incontinence of urine/ faeces
- Personal hygiene- head to foot care
- Prevention and care of pressure sores

### Basic care in bedridden patients includes:

1. Personal hygiene- Head to foot care.
2. Nutrition-oral intake or Naso gastric feeding
3. Exercise (passive & active)
4. Bladder care
5. Bowel care
6. Communication
7. Assessment of symptoms, recording and reporting.

#### ***1. Personal hygiene-head to foot care.***

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

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

#### **Purpose**

- To keep the hair clean and healthy
- To promote the growth of hair
- To prevent loss of hair
- To prevent itching and infection
- To prevent accumulation of oil, dirt and dandruff
- To prevent hair tangles
- To provide a sense of well-being
- To stimulate circulation
- To destroy lice
- To appear well groomed

**Points to remember while giving 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.

**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 canthus with separate swabs, daily 3 or 4 times with boiled cooled water.

**Care of nose and ears**

The nose and ears need minimal care in the daily life. Excessive accumulation of secretions makes the patient to 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.

When there is poor hygiene of the ears, debris may accumulate behind the ears and in the anterior aspect of the external ear. Another common problem is the collection of ear wax which can be easily removed by instilling vegetable oil or warm liquid paraffin. When it cannot be removed, consult ENT surgeon.

**Mouth care**

Mouth care is provided to maintain the integrity of the patient's teeth, gum, mucus membrane and lips. If the patient is conscious, assist the patient in his mouth care. If the patient is unconscious, the carers need to be empowered regarding mouth care by demonstrating the procedure.

Solutions which can be used are - Normal Saline, Soda bicarb, lime juice, neem leaves boiled in water, tooth brush and tooth paste.

**Routine mouth care**

- Recommended daily assessment
- Brush and rinse mouth at every 12 hour interval or according to the patient's condition.
- Soak dentures overnight
- Apply lip balm for cracked lips

**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 dehydrates and lemon over stimulates salivary glands.

**Assisting the patient with oral care**

- Explain the procedure to the patient.
- Help the patient if not able to do or assist the patient with the required materials.
- Assemble the things needed for mouth care.
- Toothbrush, toothpaste, small basin, water in a jug, towel, lip lubricant.
- (Needs demonstration)

### **Providing oral care for the dependent patient**

- Explain the procedure to the patient.
- Assemble the things needed for oral care.
- Put the patient 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.
- Soda bicarbonate 1 tsp in one pint of water.
- One tsp of salt in 500ml of water boil and can be used for oral care.
- Remove all the water from the mouth so as to prevent aspiration.
- Keep the patient on side lying position so as to drain excess of secretions.
- (Demonstration.)

### **Skin care**

#### **Bed bath**

Bathing is very important in maintaining and promoting hygiene.

#### **Purpose of bed bath**

- 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 wellbeing.
- To regulate body temperature.
- To provide active and passive exercises.

#### **General instructions for giving bed bath**

- Maintain privacy
- Explain the procedure
- Patient's room should be warm and free of draughts.
- All needed equipments 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 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 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 finger nails and toe nails.
- 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 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 by moisture, pressure, friction and dirt.

- 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 parts.
- The temperature of the water should be adjusted for the comfort of the patient
- Creams / oils/paraffin are used to prevent drying and excoriation of the skin.
- Keep the patient near the edge of the bed to avoid over reaching and straining of the back of the care giver

### **Back care**

- Patients, who are prone to pressure sores, must have their back care every 2 hours or more frequently. Back is washed with soap and water, dried and massaged with any 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 – oral intake or nasogastric feeding**

Nutrition is a basic human need and changes throughout our lifecycle. Many factors affect the individual's food intake. Diet is very important in a patient to maintain his/her health. Poor nutrition leads to many health problems. Patient and family has to be educated about the importance of nutrition.

### **General instructions –**

- Diet to be planned according to the need of patient.
- Food should be served in the right quantity and time.
- Procedures to be done at least one hour before the meals.
- Serve the food in a good environment.
- In a bedridden patient assemble all the things near the patient and assist if needed.
- Easily digestible food to be served.
- Give time to the patient to eat the food.
- Talking to the patient while he/she is eating will make the patient feel good.
- Before and after food give water for hand washing and oral care.

### **Nasogastric feeding-is given to the patient who is not able to take orally**

- Give the patient 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 total 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 give 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 prevents aspiration)
- Give 2hourly feed and after 10pm (night) just two feeds at 3hours of interval.

- Prepare feed at home with what is available like vegetable and dhal 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 the importance of exercise to prevent joint stiffness. If there is no restriction or bone problems exercise can be given by the patient's family.

### Care of perineum

The perineal care is to clean the perineum 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.

Perineum should be cleaned after each act of urination and defecation. Hands should be cleaned after giving perineal care

- Clean with soap and water daily 3to4 times and keep the area dry

### Bladder Care

Bladder care is important in bedridden and catheterized patients.

#### How to help patient suffering from incontinence?

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

#### Patient with indwelling catheter needs the following:

- Clean 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 3weeks
- 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 3/4<sup>th</sup> full.
- Observe if urine is draining freely
- Secure the urobag below the waist or leg while walking.
- Observe the color and amount of urine.

**Condom catheter** – Need 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 till 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 is more

evident when the catheter is stuck around the penis allowing collection of urine around the penis.

## **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 normally supply tissue with oxygen and nutrients resulting in ischemia and possible 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 of the sore.

### **Stages of pressure sores**

1. Erythema: Skin is intact but red and does not turn white when pressure is applied
2. Breakdown of the dermis: Outer layer of the skin is broken, red and painful.
3. Full thickness skin breakdown: This involves damage or necrosis of subcutaneous tissues.
4. Breakdown of bone, muscle and supporting tissues: This involves deep wounds that are difficult to heal.

### **Nursing interventions**

#### **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
- Identification of patients prone to develop pressure ulcers
- Change the position of the patient every two hours (in lying down position) and every one 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 bed pan to avoid the friction
- provide a wrinkle free bed
- Use special mattresses like air or water mattresses Avoid poorly ventilated mattress
- Cut short finger nails
- Encourage the patient to move in the bed as far as possible.
- Change the linen as they become 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 head end of 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. 4 points to remember

- Maintain daily hygiene with 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 need 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 family about care procedures.

## Bowel Care

Constipation is more common than diarrhoea. Efficient bowel management alleviates distress of patients and carers. Carefully assess bowel function on a daily basis.

**Constipation: Take** a detailed history followed by PRE (per rectal examination) Passage of hard stools is difficult and painful. Always compare with a patient's normal 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. So encourage deep breathing, abdominal massage etc. Encourage intake of fibre rich diet and fluids.

### Prevention of constipation:

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 physical limitations permit.
- Maintain adequate oral fluid intake. Constipated stools have relatively low water content, rendering them hard and difficult to pass. Adequate fluid intake is therefore helpful.

- Use of bedpans: It is mandatory to maintain patients' privacy and use of a commode or lavatory for defecation.

### Communication/psychological support

This is very important in bed ridden or chronically ill patients. Good communication skill can improve patient's quality of life.

#### Important messages

- Assessing and identifying the problems of the patient.
- Prioritizing the patients problem and managing it.
- Involving the patients family in the care
- Strengthen the carer in performing the procedures.

### Self-assessment questions

1. How to educate about assessing and identifying the problems of the patient and family?
2. How to use the available resources in the home care setting?
3. How to improve the quality of life of the patient?
4. How to strengthen the candidates in delivering the care?

### Malignant wound care

#### Learning Objective

At the end of this session, the candidate should be able to:

- Understand the importance of caring for cancer wounds and how to care for each problem in a cancer wound.
- Manage malodour and excess exudates in a malignant wound.
- Reduce pain before dressing.
- To prepare saline and dressing materials.
- To do a good dressing

#### Introduction

Cancer wounds are very distressing for patients. cancer wound looks like cauliflower. These cancer wounds may develop during the last few months of life.

### MANAGEMENT OF CANCER WOUNDS

- Minimize pain, infection, bleeding, odour and psychological trauma.
- Prevent maggots
- Treatment should be realistic and acceptable to the patient and carers.
- The primary aim is the promotion of comfort and the enhancement of quality of life.
- Following assessment, choose a dressing regime to meet the needs of the patient.
- Be prepared to change and experiment since there are no 'rights' or 'wrongs'.
- Simple dressing materials which can be sterilized in a 'pressure cooker' at home are affordable options.
- The simplest products may be the best and the most cost- effective. The criteria are comfort, acceptability and availability.

**Physical problems**

- Location of the wound.
- Bleeding
- Infection
- Malodour
- Pain related to dressing changes

**Psychosocial problems**

- Body image
- Denial
- Depression
- Embarrassment
- Fear
- Guilt
- Impact on family
- Loss of self-respect.
- Tunnelling/undermining.
- Discomfort of dressings
- Social isolation
- Social support/resources

**1. Management of malodour**

- Wound malodour is probably the most distressing symptom for patient's family and caregivers, as wound malodour may be constantly detectable and can cause vomiting. The presence of a pervasive malodour can lead to embarrassment, disgust, depression and social isolation and may effect on sexual expression causing relationship problems.
- Antibiotics destroy the bacteria responsible for malodour. Through bath 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 to keep malodour under control.

**2. Management of exudates**

- Cancer wounds often produce excessive amounts of exudates 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-adherent 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, in some cases, reduce pain.
- Complementary therapies can play an important part in pain management; therapies such as relaxation, distraction or visualization may help anxious and stressed patients

#### **4. Management of Bleeding:**

- Wound bleeding is common in cancer wounds.
- Always mask the bleeding with dark coloured clothes.
- If dressings are not soaked, bleeding may occur.
- Bleeding occurs when cleaning roughly.
- Preventive measures are important to reduce the risk of bleeding.
- Using non-adherent dressings that maintain a moist environment, and cleansing by irrigation rather than swabbing, will reduce the risk of trauma and subsequent 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 in to 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
- keep the wound always covered to prevent maggots

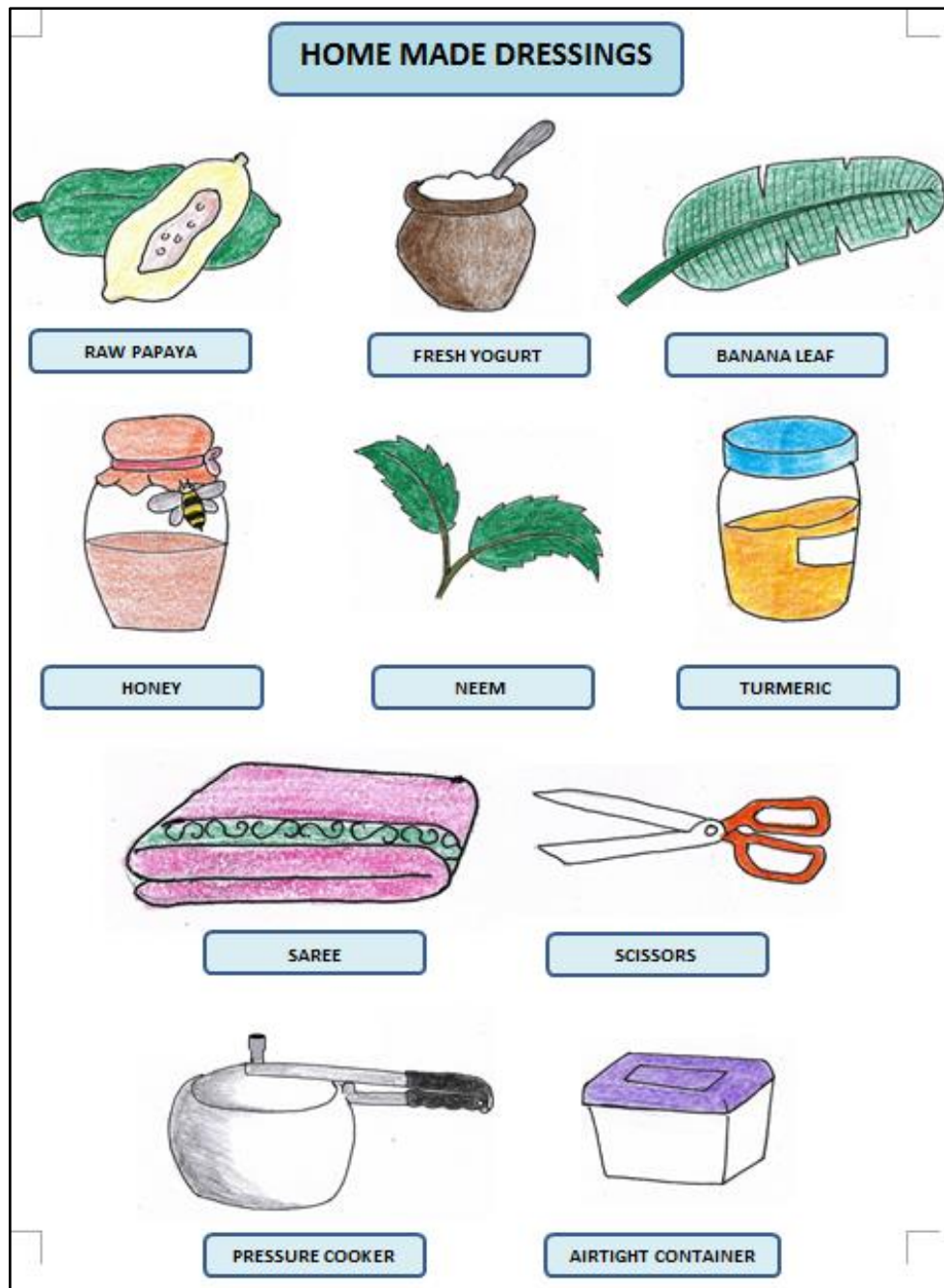
#### **6. Management of Infection:**

- Thorough bath before dressing reduce malodour, infection and washes off exudates.
- The wound should be cleaned with normal saline or preferably under running water.

#### **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 a idly vessel or in a wide mouth open vessel and boil for 20minutes. Preserve these sterile dressings' materials in a clean container. Repeat sterilization every third day.
- Preparation of saline- in 500ml of water adds 1tsf of salt and boil for 10minutes.
- Preparation of Vaseline gauze: Gauze can be cut into desired size, smeared with Vaseline, piled up and sterilize 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 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 healing of bed sores along with other measures.
- 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.



**Important messages:**

- Give realistic hope to the patient and family about the wound
- Handle gently the cancer wounds while dressing
- Educate the carer how to do a dressing
- Teach the carer how to prepare saline and dressing materials in home care setting.

**Self-assessment questions:**

1. How to identify the problems and prioritize according to the issue?
2. In emergency situation what step to be taken?
3. How to improve the quality of life of the patient?
4. What steps to take to empower the candidates for rendering the care?

**Tracheostomy care****Learning objectives**

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

- Identify tracheostomy outer and inner tube.
- Empower the patient and family in cleaning the tracheostomy tube.
- Educate the patient and family about speech therapy

**Teaching notes**

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**  
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**  
The 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 seen in patients with tracheostomy**

- 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 sterilize it by putting it in boiling water for 5 minutes. Then re insert it, and lock it.

- 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 in to 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

## **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. Tie should be changed when it is dirty. Tie should be changed by trained persons.

## **6. Speech therapy and communication**

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

## **7. Prevent the entry of water directly in to the stoma while bathing, swimming, and shaving**

### **Important messages**

- At any point not to remove the outer tube.
- Not to change the tie without the help of a trained person.

## **Self-assessment questions**

1. How to clean the inner tube and the skin?
2. How to change the tie of the tube?
3. How to bring out the thick secretions without suctioning?
4. How to educate about speech therapy?

## **Ostomy care**

At the end of this session, the candidate should be able to:

- Improve the quality of life of the patient.
- Involve the family in the plan of care
- Assess the physical, psychological and social issues.
- Give awareness about the stoma care.

### Teaching notes:

**Ostomy:** an opening created in the body for discharge of body wastes.

Stoma (Greek word meaning - mouth or mouth like opening) is an artificial opening that is surgically created in the body.

### Types of ostomy:

- Input: Tracheostomy, Gastrostomy, Feeding jejunostomy
- Output: Colostomy, ileostomy, Urostomy Colostomy

### Assessment of stoma

- Stoma colour- Normal colour is deep pink to deep red and should be checked regularly.
- Stoma bleeding- The stoma may bleed can be managed by the application of pressure.
- 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 supine position it usually reduces. But in some cases, the hernia does not reduce and this should be reported immediately.
- Stoma prolapse- occurs as a result of weakened abdominal wall caused by abdominal distension and needs surgical intervention.
- Retraction of the stoma- stoma withdraws inside.

### 1. Care of skin:

- Clean the skin with soap and water
- Keep it clean and dry with a soft cotton cloth.
- Use correct size bag
- Empty the bag when it is  $\frac{3}{4}$  full
- Patients with sensitive skin- should use simple pouching system
- Avoid powder or cream on peristomal skin.
- For skin excoriation, apply Zinc Oxide with oil
- Use antifungal powder in case of fungal infection
- To prevent bad smell, put a small piece of charcoal in the colostomy bag.

### 2. Diet:

- Reduce food items that give smell e.g.: cabbage, meat, garlic, onion etc. Minimise use of chillies and spices in food.
- Use same type of cooking oil to prevent diarrhoea
- Colostomy patients should have fibre rich diet and more fluid intake to prevent constipation

### 3. Games:

- Avoid rough games to prevent stoma injury

#### 4. Travel:

- Protect stoma with a bag or a book. Keep extra colostomy bag while travelling

#### 5. Sexual life:

- Support, advice, encouragement and counselling.

### Ileostomy

- It is created to divert stool away from the large intestine and the output is usually soft and unformed stool. An external appliance is worn to collect the stool and needs to be changed.

#### Important messages

- If colostomy is done on descending and sigmoid colon patient can practice colostomy irrigation.
- Awareness about the stoma has to be given to the patient/family and about the care.
- To treat the stoma as normal opening.

### Self-assessment questions

1. How to empower about the colostomy care?
2. How to assess the stoma and manage the problems?
3. When to seek the doctor's advice?

### Lymphedema management

At the end of this session, the candidate should be able to:

- Identify lymphoedema.
- Provide skin care in lymphoedema.
- Impart health education about lymphoedema

### Teaching notes:

Lymphoedema is accumulation of lymph in the interstitial space of subcutaneous tissue.

Lymphoedema can be primary or secondary.

- **Primary:** Congenital
- **Secondary:** It can be the result of an infection, injury, cancer treatment, inflammation of the lymph, or lack of limb movement.

### 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 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 corner stone's of management**

1. Skin care: to keep the skin in good condition and reduce the chances of infection.
2. Compression (bandage / Hosiery)
3. Massages
4. Exercises

### **Skin care: -**

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

Lymphoedema should be managed by a trained specialist. Compression with bandage or stockings, massage and exercises, these steps of lymphoedema can be taught to the patient and family members. Give awareness to the patient and family about lymphoedema and about the management.

### **Important messages**

- Lymphoedema can be prevented by following simple management.
- Identify lymphoedema at the earliest.
- Simple techniques can manage lymphoedema.

### **Self-assessment questions**

1. What awareness to give the patient about lymphoedema care?
2. What are the clinical features of lymphoedema?
3. How to manage the lymphoedema?
4. How to prevent the development of lymphoedema?

### **Conclusion:**

Nursing issues in a chronically ill patient and giving nursing care in the home care setting is challenging for a health care provider. Reaching out to patients place and giving the care with

available materials or support really needs the acceptance of the community. ASHA workers can render this support by giving regular awareness in small groups. Demonstration of the procedures will help the family to care for their patient and improve the quality of life of the patient

### **Assessment of symptoms, recording and reporting**

Assessment of symptoms is very important to give good patient care. While communicating with the patient go into detail history and record it and if any symptom needs management report it immediately. With physical issues, give importance to the psychosocial, spiritual and financial problems. This given tool will be helpful in assessment.

Symptom assessment acronym:

- **O**- Onset – when did it begin? How long does it last? How often does it occur?
- **P**-Provoking/palliating – what brings it on? What makes it better? What makes it worse?
- **Q**-Quality – what does it feel like? Can you describe it?
- **R**-Region/radiation – where is it? Does it spread anywhere?
- **S**- Severity – what is the intensity of this symptom? Any other symptom accompanies this symptom?
- **T**-Treatment – what medications and treatment are you currently using? How effective are these? Do you have any side effects? Any past treatment?
- **U**-Understanding/impact on you – what do you believe is causing this symptom? How is this symptom affecting you and your family?

Documentation is very important. Record in detail the problems of the patient and family. Report the issues in the nearest primary health center. Give review dates according to the condition of the patient and make a regular follow up.

## Chapter 7

### Psychosocial and spiritual support in palliative care

**Time-** 90 mins

#### **Learning objectives**

At the end of this session, the candidate should be able to:

- Acquire an understanding about the psychological and spiritual issues related to palliative care and in patients with chronic illnesses;
- Manage delirium, anxiety and depression in patients undergoing palliative care;
- Recognize psychosocial and spiritual needs of patients and caregivers;
- Develop empathic listening skills, identify and respond to emotional and spiritual distress when it occurs.

#### **Training methodology**

**Power point presentation / Blackboard/ lecture –10 minutes**

#### **Activity 7.1 - 20 minutes**

Bhola Ram, a 25 -year-old construction labourer, fell from a roof -top with spinal cord damage and paralysis of both legs. He has been discharged from the hospital and is at home. He is on a catheter to pass urine. He has two children, aged 3 and 1 years. His wife is unable to go out 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

- Mobility
- Activities of daily living
- Finance
- Personal relationships
- Sexuality
- Social activities
- Transport
- Work/capacity to work
- Home environment
- Carer issues
- Health and social care: accessibility and quality
- How can you help him?

**Discussion in groups - 10 minutes**

**Report back - 5 minutes**

**Summary-** 5 mins

### Activity 7.2- 20 minutes

Which transport facilities are available for patients in the area? Pool the details of government and non-government agencies in the area which can help with transportation

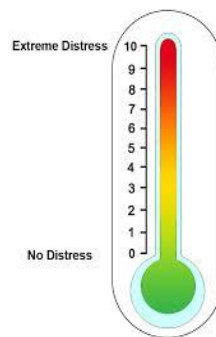
Pool the details of government and non-government agencies in your area from which a patient/family can get medical/ social/financial support. Develop this into a sharable resource list for the area.

**Discussion in groups-** 10 minutes

**Reporting -** 10 minutes

### Activity 7.3

**Demonstrate and discuss Use of emotional distress thermometer and need to refer if showing signs of depression.**



**A persistent score of more than 5 may indicate a need to seek professional help.**

### Activity 7.4- 10 minutes

1. How will you define spirituality?
2. What is its relationship with religion?
3. What do you consider as a spiritual issue? One example?

**Brainstorm** in small groups -5 minutes

**Share** with others -5 minutes

### Activity 7.5 - 10 minutes

**Encourage** one person in the group to read out the definition and explain.

**Facilitate** a discussion -10 minutes

#### **Activity 7.6** - 10 minutes

**Look** back on your life and reflect on an event or experience you consider as meaningful.

Share with others if you feel so

(2 minutes for reflection; 8 minutes for sharing by those who want to volunteer).

#### **Activity 7.7** - 10 minutes

How can you support a patient who has spiritual needs?

**Interactive discussion-** 10 minutes

### **Teaching notes:**

#### **Introduction**

As a frontline health worker 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 most valuable thing you have to offer someone else is YOU. Being consciously aware of your own behaviour, what you say and do, and how you conduct yourself, makes or mars the contact with the patient and family. Remember, what the person you visit will remember most clearly is you, not what you did or said.

This is why before anything else, you need to reflect on what kind of beliefs and prejudices you have that may facilitate or impede the process of rapport building.

This handbook will help you understand what is meant by psychosocial distress in palliative care. It will show how you can make a positive difference by developing listening skills and creating an environment that will allow another person to share their emotions with you. This is known as empathic communication.

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 own losses in their own way. We are there to walk with them in that journey, not to tell them what to think, feel or believe. It is therefore important that we don't try and take the suffering away by trying to impose our own spiritual solutions onto their spiritual struggles. This handbook outlines how this can be done.

#### **Content**

##### ***1. Psychosocial and spiritual needs of patients and caregivers***

Each one of us deals with a chronic, life altering and debilitating illness, as well as with the possibility of dying, in our own unique way. Our age and level of maturity, our socio-economic status, our personality, all play a role. However, on the basis of numerous studies and observations, the following emotions have been identified as most likely to influence the behaviour of a sick person:

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

These emotions are a result of the difficult circumstances that people find themselves in which rob them of their previous sense of normalcy and security. They may also test and alter relationships within the family and with friends.

**Patient's reality as illness progresses:**

- Dependent on others
- Loss of confidence and control
- Feelings of guilt; of becoming a burden
- Fear of suffering and death

**Patient's needs:**

- To participate in own illness
- To be treated with respect
- To be heard and to ventilate feelings
- To continue to live with dignity
- To resolve conflicts
- To receive peace and forgiveness
- To get permission to die

**Family's reality as illness progresses:**

- Exhausted
- Feel alone
- Anxious & Depressed
- Uncertain about future course of action
- Lack of finances/resources
- Unable to see or maintain hope

**Family's needs:**

- To be able to express feelings openly
- To ask questions and receive honest answers
- To get help to resolve family conflicts, etc.
- To get reassurance and information
- To receive affordable medical, nursing and emotional support

As caring medical professionals, we must respect the right of patients and their family members to feel the way they do and help them talk about what they are feeling without judging them. This requires empathic communication.

## **2. Empathic communication**

Empathic communication requires basic listening skills and the ability to give an empathic response as required.

First, you need to do a self-assessment.

1. What kind of a listener am I?
  - Pseudo-listener (pretend to listen but not really interested)
  - Selective listener (listen only to what suits me)
  - Stage-hogger (only talk; do not listen)
  - Insensitive listener (interrupt frequently, show irritation, etc.)
2. What are my biases and emotional triggers?
  - Do I believe people get what they deserve?
  - Do I have sympathy for people who drink and smoke?
  - Am I uncomfortable talking about sickness and death and dying?
  - Do I favour a particular caste or community over another?

Second, you need to understand the emotional needs of patients and their families. This is best done by putting yourself in other person's shoes. How would you feel if you were sick and dependent on someone else for even basic tasks? What is it like to nurse someone who requires constant attention?

Third, you need to develop the skills of empathic listening which at the very least require the following:

- Observing your surroundings when you enter a patient's home
- Spending adequate time with the patient and family
- Listening for the feelings behind the words, including non-verbal cues
- Being encouraging and reassuring; maintaining realistic hope
- Providing information as and when needed
- Letting them know when and where you can be reached
- Keeping appointments
- Maintaining confidentiality

**The benefits of empathic listening are many:**

- It removes uncertainty; patient copes better

- Patient and family can make informed choices
- Prevents unrealistic hope and loss of scarce resources
- Gives opportunity to express emotions
- Leads to better compliance as patient and family move from denial to acceptance

**In the Indian situation, we are often faced with dilemmas based on our culture:**

- Who to communicate with?
- What to communicate?
- How to communicate?
- When to communicate?

**While there are no easy answers, as every situation and family differs, as a rule of thumb the following may be kept in mind:**

- Focus on patient and main decision maker
- Gauge readiness of patient and family to accept the truth
- Give bad news in small doses. This allows the patient and family time to absorb the information being given.
- Respect silence. Do not rush in. Wait for a response.
- Do not answer direct questions such as, “When will I die?” or “How long do I have?” Instead, explore further. Ask a counter question like, “Why do you ask?” or “Is there anything in particular that you want to do?”
- Do not neglect children, as they are also part of the family dynamic.

**Like anything else, listening needs to be practiced so that it becomes effortless. Here are a few useful tips:**

- Ask open-ended questions like “How are you feeling?” or ‘what is your concern?’
- Reflect what is being said: “so what you are saying is that you feel very angry because...”
- Clarify/Do not assume

### ***3. Recognising and responding to psychosocial and spiritual distress***

Medical professionals must do a psychosocial assessment of the patient:

- The nature of the patient’s mood- “How exactly are you feeling?”
- The severity- “How bad does it get?”
- The frequency- “How often do you feel this way?”
- The duration- “How long does it last?”
- The triggers- “Is there anything that makes it worse?”
- The impact- “How does this affect your day-to-day life?” “How does it affect you?”

The same may be done for the main caregiver. This will help identify psychological trauma as well as signs of depression. It will also bring to light spiritual distress because of unresolved family matters related to forgiveness, feeling that God has abandoned them, fear of punishment after death, etc.

After the assessment, one must deal with these issues as best one can or, depending on their severity, refer them on to a specialist.

### **Dealing with emotional issues:**

The majority of patients will have unfocused anger which may even be directed at you. The best way to deal with this is to listen without interruption. By the time they finish, they will be relieved of their anger and grateful to you for giving them the opportunity to express themselves.

Fear is another common emotion, if not openly expressed it will continue to grow. Patient's often have unfounded fears that can be relieved through discussion. They should be encouraged to list their fears and prioritize them so that they can be dealt with one at a time. This makes fear more manageable.

There are patients who become uncommunicative and withdraw. Do not assume that they do not want to talk. Consider why they have withdrawn. Here are a few possibilities:

- Fear
- Embarrassment (perhaps due to disfigurement)
- Depression (sense of worthlessness)
- Confusion (feel rejected and lost)
- Anger
- Denial
- Think no one is interested in them
- Suspicion/Lack of trust
- Physical disability (for example have lost voice-box)

Very often after the death of patient, caregivers feel guilty. They feel that they did not do enough: "If only I had had more money?" "If only I could have taken him or her to a particular hospital?" etc. The best way to deal with this is to ask the caregiver to make a list of the things they did do for the patient. This will help them realize that they have done a great deal and make them less guilty.

Shame and stigma tend to be associated with diseases such as cancer and HIV/AIDS. It is important to talk openly with the patient and the family and to answer all their questions. Over time, a shift in attitude is likely to take place.

Never forget hope; it always has a place no matter what the prognosis. Our task is to foster it at all stages but not to give false hope. We must find out what the hopes of patients are by asking them. The same holds true for caregivers. We may ask: "What is your hope for your loved one?" Usually what patients and caregivers are looking for is more control over their situation so that they can move from a feeling of helplessness to one of hope.

### **Dealing with spiritual issues:**

Patients who are dying often ask questions like: "How much time do I have?" "When will I die?" "What will happen to me after I die", etc. It is best to help them explore their fears and respond with empathy rather than provide answers. This is not the occasion or time to inflict your own religious belief or personal point of view on the patient.

Patients often confide that they wish to go to God in peace. More often than not what they are asking for is help to resolve some unfinished business. It could be need for forgiveness from a loved one, reconciling with an estranged relative, or reaching out to someone who has rejected them. It is a good practice to ask permission from the patient and the family, before you reach out to the concerned person on their behalf.

There are patients who talk about ending their lives. As palliative care practitioners, we believe that this is a cry for help that can be met with the right medical, nursing, psychosocial and spiritual response. However, we should remain vigilant to suicidal tendencies, to clinical depression and to mental illnesses that may predispose patients to take this extreme step. We must direct them to the appropriate consultant.

This holds true for the bereavement phase too. There may be caregivers who are finding it difficult to cope with loss and grief after the death of a loved one. This may be compounded by poverty, especially if the person who died was the main bread-earner. While grief is natural we should be able to recognize grief that refuses to resolve. Parents often find it difficult to accept the death of a child. Caregivers may also have their own set of spiritual questions at this stage: “How is my loved one?” “Where is he or she now?” “How could God allow this?” “Will I see them again when I die?” Once again, it is not the answers we give that matter as much as how comfortable people are to discuss their deepest feelings with us and thereby find inner peace.

## **Conclusions**

1. Palliative Care is incomplete unless we address psychological and spiritual issues of patients and their caregivers.
2. Often our attitudes and biases stand in the way of us becoming effective healers. Self-reflection must go hand in hand with the acquisition of knowledge and skill.
3. By using the technique of empathic listening we can encourage people to express their emotions and share their anxieties which will help them cope better.
4. Empathic communication requires hard work and practice.  
It is about:
  - Relationship building
  - Observation of the patient and family
  - Identification of the main problem
  - Formulation of goals
  - Assessment and evaluation
  - Referral where needed
5. As health care professionals on the frontline, we should be conscious of our limits and should be able to refer psychosocial and spiritual distress to the requisite specialist, whether it is a doctor or a priest.

## **Self-Assessment Questions**

2. Which of my beliefs causes me to interpret the actions of others in a negative way?

3. Can I listen to someone without interrupting and giving advice?
4. How do I respond to emotions such as anger, fear, guilt, shame, etc.
5. What is the level of my spiritual awareness?
6. How do I view death and dying?
7. Do I have the capacity to express compassionate love towards patients under my care?
8. Do I recognise my own personal and professional limits?
9. Am I ready to seek help for myself if necessary?
10. Am I capable of maintaining confidentiality?
11. Where do I stand on the question of euthanasia?

## Chapter 8

### End of Life Care (EOLC)

**Time:** 60 minutes

#### **Learning objectives**

At the end of this session, the candidate should be able to:

- Improve end of life care for the terminally ill
- Ensure comfort and dignity
- Engage in a good communication with patient and caregivers

#### **Training Methodology:**

**Power point presentation/ Blackboard/ Lecture-** 10 minutes

**Activity 8.1** - 15 minutes

#### **Group discussion**

What are the rituals carried out in your area before and after death?

**Discussion-** 10 minutes

**Reporting-** 5 minutes

**Activity 8.2** - 15 minutes

#### **Grief and Bereavement**

**Discuss experiences:-**

- How do people react when their loved ones die?
- How long do people take to recover?
- What can we do to help them?

**Discussion-** 10 minutes

**Reporting** - 5 minutes

**Activity 8.3** - 10 minutes

A neighbour is willing to offer companionship to a dying patient and his family after he dies. What sort of training will he/she need? (Refer also to the session on communication to patients.)

**Generate** a data sheet with details of professional psychologists/counsellors in the area

**Preparation-** 5 minutes

**Reporting-** 5 minutes

#### Activity 8.4 - 10 minutes

##### Discuss with the participants-

- How is 'death at home' certified in your village?
- Who are the resource persons? Make a list and share

##### Discussion- 10 minutes

##### Reporting- 10 minutes

#### Teaching notes:

**End of life Care** is an approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life.

The **terminal phase** is when day to day deterioration, particularly of strength, appetite and awareness is occurring.

#### How to recognize the terminal phase?

*Remember, these signs and symptoms are just relative...wide variations can occur and hence it is not possible to predict the terminal phase with accuracy.*

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

*Be aware that improvement in the general condition of the patient or other functional observations could indicate that the person might be stabilizing.*

#### Goals of care

- **Explaining and communicating** with caregivers, so that they are mentally prepared
  - Explore their level of understanding
  - Have a person important to them be present during the discussion
  - Explore if they wish to know more about the prognosis and discuss accordingly
  - Address their fears and concerns and provide contact information (ambulance, your contact, nearest doctor, hospital, etc.)
  - Explore if they have any religious, cultural, social or spiritual needs
  - Explain the uncertainty surrounding the timing of dying
  - Document the discussion along with the names of the persons discussed with
  - Discuss the case with the doctor concerned and document it

- **Ensuring and maximizing the comfort of the patient by providing 'individualised care'**
  - Assess level of consciousness of the patient
    - Explore the person's current goal and wishes
    - Record and document preferred care setting (home, hospital, etc.)
    - Explore the understanding and wishes of the dying person and of the caregivers
    - Remember...the wishes and plans may change
  - Maintaining hydration
    - If swallowing is difficult, feeding with a spoon is helpful. Ensure that the first sip has been swallowed before the next sip if given.
    - Discuss risk of aspiration
    - Encourage caregivers to give lip and mouth care
    - Use an individualised approach when contemplating clinically assisted hydration
      - Level of consciousness of patient
      - Ability to swallow
      - Level of thirst
      - Need for giving medications
      - Adverse effects of parenteral hydration
        - ✚ Technically difficult
        - ✚ Expensive
        - ✚ Labour intensive
        - ✚ Risk of infections, pulmonary edema
        - ✚ Difficult in resource poor settings
  - Review
    - All medications taken by patient with doctor to explore possibility of discontinuing 'non-important' medications
    - Decide on the most effective route for administration of medications with doctor and caregivers
      - Avoid intramuscular and intra venous routes
      - Consider intermittent subcutaneous injections [nursing issue]
      - Reassess regularly
  - **Good symptom control:** Providing '**non-pharmacological**' methods of symptom control like gentle stroking and use of fans for breathlessness, repositioning to manage pain, mouth care, pressure sore management by position change, air or water mattress, etc
    - *Control of pain:* continue analgesics after discussion with doctor. Treat reversible causes like urinary retention.
    - *Bladder and bowel:* The patient is very likely to soil the bed at this point of time. The caregivers need to be taught how to clean the patient [Nursing issue]. If needed, after discussion with the caregivers and doctor, bladder catheterization may be needed.
    - *If the patient cannot swallow,* after discussion with the doctor, and after obtaining the consent of the patient and/or caregivers, a feeding tube can be inserted. The caregivers should then be taught how to administer naso-gastric feeds [Nursing issue].
    - *Breathlessness*

- Consider non-pharmacological methods
    - Switching on fan
    - Staying with the patient and boosting morale
    - Gently stroking the back
  - Do not start oxygen therapy routinely without discussing with doctor
  - Consider drug therapy (morphine, alprazolam) after discussing with doctor and document
- *Anxiety, agitation and delirium*
  - Look for reversible causes like pain, hyponatraemia
  - Consider non-pharmacological management
  - Consider drug therapy after discussing with doctor
    - Alprazolam, haloperidol
- *Noisy secretions (death rattle)*
  - Offer explanations to caregivers
  - Ensure them that it is not a matter of distress for the patient
  - Consider non-pharmacological approach
    - Positioning of the patient (recovery position)[nursing issue]
    - Removing the secretion from angle of mouth using finger wrapped in a gauze piece by 'hooking' the finger and 'swiping'
- *Convulsions*
  - Prevent patient from self-harm during convulsions...do **not** force any object like a spoon into the mouth
  - If possible, terminate the convulsions by intravenous or intramuscular midazolam or any other drug as suggested by the doctor
  - Continue anti-epileptics as prescribed
- *Severe haemorrhage*
  - Anticipate this possibility and discuss with family pre-emptively
  - Reassure and comfort the patient and family
  - Apply firm and steady pressure where possible using dark towels
  - Sedate the patient
- **Supporting the family**
  - The family is suffering as much or even more
  - Offer explanations and anticipatory counseling for distressing symptoms and bereavement
  - Address religious, social and spiritual concerns
  - Arrange extra help, including help from a doctor
- **Confirming death at home**
  - Introduce yourself to family and explain need to confirm death
  - The family can stay inside or wait outside if they so prefer
  - Confirming death

- Wash hands
  - Confirm identity of patient
  - General inspection for obvious signs of life like movement, breathing, twitching, etc
  - Look for signs of respiratory effort
  - Does patient respond to verbal stimuli?
  - Does patient respond to pain? (supraorbital pressure, sternal rub)
  - Assess for pupil reactivity using pen torch...after death they become fixed and dilated
  - Feel for a central pulse (e.g. carotid artery)
  - Auscultation, if a stethoscope is present
    - Listen for heart sounds for at least 2 minutes
    - Listen for respiratory sounds for at least 3 minutes
  - Wash hands and exit the room
- Documentation of your assessment with date, time, name, position. Document that a family member (name and relation) has been informed about the death.
  - Inform the doctor/RMP/village Panchayat/BDO

## Chapter 9

### Community participation in palliative care

**Time:** 120 minutes

#### Learning Objectives:

At the end of this session, the candidate should be able to:

1. Understand the need for a community –based approach to palliative care
2. Comprehend the meaning of community participation
3. Obtain clarity on the role of volunteers, health professionals, CHWs and family in providing care to patients in the community
4. Devise strategies on how to mobilise the community and its impact

**Power point presentation / Blackboard/ lecture - 10 minutes**

**Activity 2.1-** 20 minutes

**Discussion-** 10 minutes

**Reporting back-** 10 minutes

Discuss the ways in which we can support a bedridden, elderly or dying patient and his/her family?

How can we find likeminded people to do this?

How can such people in an area work together?

**Field visit included**

#### Teaching notes:

##### **Rationale of Community-based Approach to Palliative Care**

People living with chronic illnesses like paralysis, cancer, advanced heart, kidney and lung diseases and old age-related problems spend most of their time at home and they are in need of regular care for the rest of their lives. For the majority of them, death is preceded by a period of suffering. This can be for days, weeks, months or years, depending on the disease process. Pain, many other symptoms like breathlessness, nausea and vomiting, paralysis of limbs, foul smelling ulcers, pressure sores, incontinence, etc. can make life unbearable, not only for that person, but also for the family. In addition to physical problems, they usually suffer from immense social, emotional, financial and spiritual issues caused by their condition. The main fears expressed by the patients are fear of death and abandonment.

They need 'total care' with support in physical, psychosocial, and spiritual areas of suffering.

### **Rationale for a Community approach to Palliative Care Service:**

- Patients with advanced diseases require continuous care and attention for the rest of their lives
- They are in need of regular social, psychological and spiritual support in addition to the medical and nursing care
- Care should be readily accessible and available as close to home as possible
- There is enough resources available in the community to build a 'safety net' in the

They prefer to be cared for in their homes and eventually, wish to die at home. The traditional hospital-based health care system cannot address these needs. It offers a patchy service through which the patient and family has access to care for a few hours/ days. In view of the nature of problem, number and geographical distribution of patients involved, community approach and home care is the most efficient way for achieving accessible and easily available services for such chronically ill patients.

### **Community Participation**

Community participation can be loosely defined as the involvement of people in a community to solve their own problems. It can mean anything from simple feedback to major involvement in all the aspects of planning and delivery of care service.

Community participation can be of two types:

**1. *Involvement of the community by utilization of community resources (money, manpower, etc.):***

Volunteers in such programs are asked to provide the resources as and when required. They do not play any major role in planning, evaluating, monitoring, or modifying the program. Most community based programs follow this model.

**2. *Involvement of community by empowerment:***

The local community is enabled to take responsibility for identifying and working together to solve their own health and developmental problems. A Kerala based community based palliative care program called Neighbourhood Network in Palliative care (NNPC) is an example of such a successful and well-known community owned palliative care program.

### **Benefits of Community Participation**

1. The patients and families benefit by accessible health service in the community.
2. The local community benefits through improving skills and confidence and the process of empowerment.
3. Awareness and acceptability to palliative care and developing a more positive outlook towards incurable diseases.
4. The potential to make health services more inclusive and less discriminatory
5. It stimulates critical thinking and act as a catalyst to address the social and cultural determinants of poor health and bring reforms.
6. It can help hold systems accountable. The community can ensure that health services and facilities are accountable to community needs and provide quality in care delivery.
7. Communities can promote good health seeking behaviour

## Components of Community Based Palliative Care Program

There are two major components of a community owned/based palliative care system:

1. Community volunteers
2. Health care professionals

### Community volunteers

A volunteer is someone who works for a community because they choose to do so. Volunteers are the backbone of a good community based palliative care program.

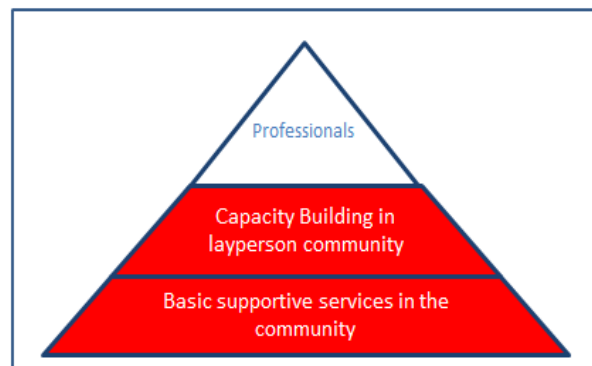
### Community volunteers' manpower is of two types:

#### 1. Untrained sensitised volunteers:

They provide the groundwork for the palliative care service by establishing a social support system, e.g., food for patients, spending time with the patient, respite to the family, transport, educational support for children and working with the local government.

#### 2. Trained Volunteers:

Some of the sensitized and motivated volunteers undergo a formal training in palliative care and get involved in direct patient care, e.g., providing emotional support, basic nursing chores, help with mobility, medication management etc.



### Roles of Community Volunteers in Palliative Care:

Volunteering in palliative care may come in many forms such as providing

- Emotional support
- Basic nursing care
- Follow up of professional home care
- Linking up with the professional team
- Social support to the affected family by way of
  - Food for the family
  - Educational support for children
  - Helping with transport to hospital
  - Linking with other support groups
  - Helping to make potential benefits from government / NGOs available
- Rehabilitation
- Community volunteers can take up responsibilities related to organisation and administration of services such as
  - Regular awareness program in the community
  - Training the family members to look after the patient
  - Training volunteers in the community

- Administrative management of the unit
- Fund raising

## **Health Care Professionals**

The community volunteers need to be supported by health care professionals. They are helped with sensitization and training and in providing palliative care through home care, in-patient IP or outpatient services. Unlike the volunteers from the community, most health care professionals in the team are paid remunerations. This core team can be supplemented with additional voluntary efforts from other health care professionals, if available. A community level care should have a good linking up with a primary, secondary and tertiary health care system for any referral or interdisciplinary support.

## **Role of a Community Health Worker (CHW)/ Multipurpose Health Worker In Community Mobilisation and Involvement In Palliative Care**

Community health workers in palliative care are often members of the communities where they work, and are selected and answerable to the communities for their activities, are supported by the health system but not necessarily a part of its organization. They undergo basic training in providing palliative care.

Community /Multipurpose Health workers play an intermediary role between communities and the health sector. As they are embedded in the community, they are able to respond to the communities' needs and realities. CHW play a critical role in fostering the interpersonal, institutional, and community relationship and trust.

## **Role of a Family**

Family and friends play a critical role in providing the round-the-clock care to patients in their homes. The health care providers like doctors, nurses and multipurpose health workers can empower the family by education and training so that they perform the daily tasks involved with caring of palliative care patients. This can be done better with the support of the community volunteers.

## **How to Mobilize a Community?**

To raise levels of awareness and sensitization can be a key aspect of engaging and mobilizing a community

## **Community mobilisation**

It applies to the way in which people can be encouraged and motivated to participate in programme activities. To raise levels of awareness and sensitization can be a key aspect of engaging and mobilizing a community.

Repeated meetings with selfhelp groups, organizations of women and elderly citizens, village administration, schools, involvement in festival and religious gathering etc are helpful in

spreading awareness and garnering support within the community. It is important to ensure that minority groups, low status groups and poorer groups in the community are not left out and that women, men and children are specified in consultation processes.

### **Funds Generation in the Community**

Community ownership can come with a good financial support within the community. A finance generating activity may be a key starting point in giving communities greater responsibility, removing dependence on external support and promoting sustainability. It may be in the form of micro funding such as accepting small donations by placing donation boxes at public places, collections from student community, donations of cash and kind during festive occasions etc. Economic rehabilitation of the patient and families by trade and service provision like setting up a small groceries or vegetable shop, tailoring, haircutting saloon etc can also be considered depending on existing skills and needs within the communities.

### **Impact of a Successful Community-based Palliative Care Program**

If any program is effective and successful, it is easier to advocate with the government to integrate it into the mainstream health policy and implementation. Kerala was the first state to roll out a very successful model of community based palliative care program. This influenced the state Government to roll out a first ever-state health care policy on palliative care in the country in 2008 and a successful implementation of an effective palliative care program in terms of quality, coverage and sustainability.

Recognising the need of palliative care as a primary health care and as a supportive care for disease specific treatment, the government of Kerala has introduced a Kerala State Policy for Pain and Palliative Care Services. Other States like Karnataka and Maharashtra have done so too. Other States are in the process of coming out with similar policies

# Annexes

## Annex 1

### Suggested Palliative Care Screening Tool for ASHA

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 and diagnosis:		
	<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 <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	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)	
<i>Cut off of 5 or more will be considered for referral for palliative care services</i>		

## Annex 2

Institute of Palliative Medicine, WHOCC for Long-term Care & Palliative Care, Kozhikode

### HEMECARE PROTOCOL

#### Initial Assessment

Home care team : \_\_\_\_\_ Date and Time : \_\_\_\_\_

Ref No. : \_\_\_\_\_ Name of Patient : \_\_\_\_\_ Age/ Gender : \_\_\_\_\_

Diagnosis : \_\_\_\_\_

1. Condition of the patient at the time of visit (What is patient doing and general condition)
  - a. Mobility (able to go out/ able to go inside and outside without help or assistance/ able to move with assistance/bedridden but can sit out without help/ can sit-up with help/ completely bedridden
  - b. Activities of daily living
2. Presenting problems (list of major symptoms, prioritization from patient side, assessment and evaluation of each symptoms)
3. Primary needs of patient
  - a. Appetite/interest in food/ food habit
  - b. Sleep- good sleep/satisfactory/ patients perception about his/her sleep
  - c. Bowel habits – daily and how many times? Hard/loose/difficulties in passing/ incontinence/privacy/ needs assistance

- d. Bladder habits – passing without difficulty/if difficulty, details of problems/color/ pain while passing urine/whether catheterized? If so urine output/color/catheter size/last catheter change-catheter care and advice to the care
4. Check the vital and record
  - a. Blood pressure and pulse
  - b. General hygiene bath/ sponge bath/ how many times/ need assistance or not
  - c. Oral hygiene and dental hygiene ( candidiasis/sore mouth/ redness/ fistula/ teeth-present or not/pain)
  - d. Perineal care (examine and make sure
  - e. Skin condition/pressure points
5. Any special care given  
 Pressure sore (site, size, shape, stage, edge. Granulation, epithelialisation, undermining and tunneling). Fungating wound/PVD/ diabetic wound( wound due to cancer or any other diseases. Present condition of the wound, wound size, site, malodour, bleeding, necrotic tissue, exudates.  
  
 Any other problems/care given (lymphoedema, colostomy, tracheostomy, gastrostomy paraplegia, hemiplegia)
6. Ask patient's/family 's spiritual, mental, financial, social problems. Document priorities (what the patient feel about the disease/ how does he see the future/their opinion about present treatment/whether able to adjust with present situation)
7. Other treatment taken after last OP/ home visit/ if so what, whether admitted/taking any other medicine/done RT& CT or any other type of treatment.

8. Whether volunteer from the clinic visit the patient or not? When was the last visit?

9. Any other comments/ rehabilitative support provided

10. Whether taking medicines regularly ( medicine not taken properly to be recorded)

11. Interventions

12. Future plan

## Annex 3

### CONSORTIUM OF PALLIATIVE CARE CLINICS, Kozhikode

#### Nurses Home Care Review

Date: .....

Name:..... Age:..... Sex: .....

Place:..... Ref No: .....

-----  
-

Team Leader:

Members:

-----  
--

Diagnosis & persistent physical problems

Condition of the patient at the time of home visit

Conscious level : Normal/Different. Describe if different.

Dependence for Activities of Daily Life; Describe

Presenting problems

Primary needs (Describe if 'different')

<b>Food</b>	Normal/ Different	
<b>Sleep</b>	Normal/ Different	
<b>Bowel habits</b>	Normal/ Differen	
<b>Bladder habits</b>	Normal/ Different	

Patient's/family's spiritual/emotional/mental/social issues

## EXAMINATION

BP:	PULSE:	TEMPERATURE:
-----	--------	--------------

Check	Condition	Describe if 'different'
General Hygiene	Normal/ Different	
Personal Hygiene	Normal/ Different	
Oral & Dental Hygiene	Normal/ Different	
Skin Hygiene	Normal/ Different	
Perineal Hygiene	Normal/ Different	
Any other	Normal/ Different	

Any special care given for the following (Ulcers/Ostomies/Catheters/Tubes / Lymphoedema/ Physiotherapy/ Bed sore etc.)

Other treatment taken after the last home care visit

Present medications / care plans

Interventions/suggestions/future plans by the home care team

Rehabilitation or other supports given

Review date: ..... Name: ..... Sign

-----

Discussion Points: