

National Programme for Palliative Care

Handbook for Community Health Workers

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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)

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सत्यमेव जयते

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(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

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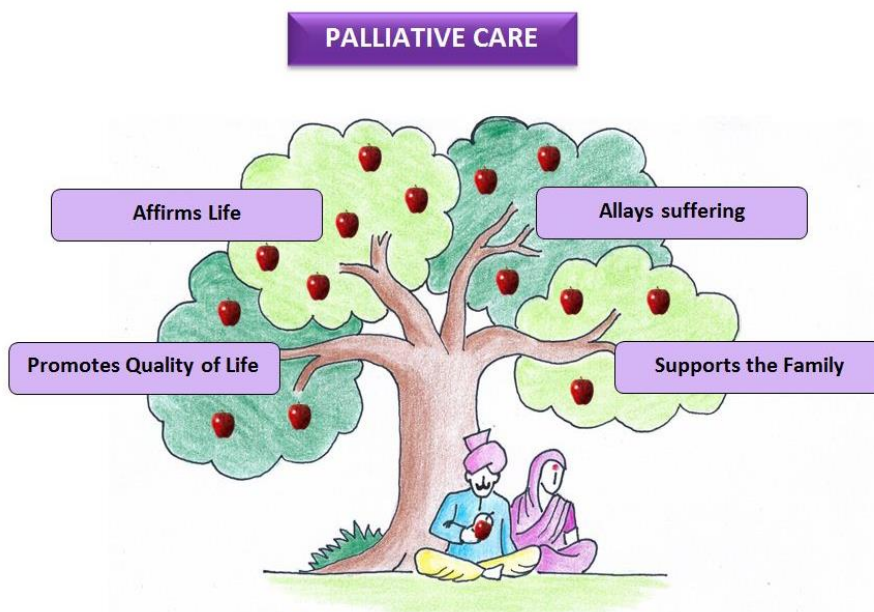
Chapter 1: Introduction to Palliative Care

What is 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.
- World Health organization says that – *'Palliative care is a way of looking at the incurable patients in a way that improves the quality of life of patients and their families. It helps prevent and relieve suffering by early recognition and treatment of pain and other physical, psychosocial and spiritual problems.'*
- 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

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 in the United Kingdom, from where it spread to other parts of the world.
- Most of the palliative care centres in India are located in the South, especially Kerala where community involvement has been the outstanding factor.
- The 'Indian Association of Palliative Care, formed in 1994. It is the umbrella organisation meant not only for healthcare workers but for all people involved in palliative care in India.



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.
- It takes care of the physical as well as emotional, social and spiritual needs of the patient and the family.
- When a patient is suffering, the whole family suffers with him so it looks after the patient as well as the family.

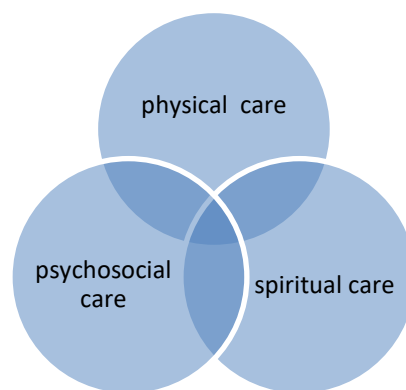


Figure 1- The principles of palliative care

Figure 1 depicts the interplay between the different elements of palliative care.

The Need

- With changing lifestyle, noncommunicable diseases (NCDs) are becoming more common. NCDs, earlier thought to be diseases of the rich, actually affect poor people more as the poor have unhealthy living conditions, poor nutrition, more high-risk behaviour and cannot afford medicines and hospitals. All this leads to more psychosocial problems.
- The maximum need is in the developing countries where two thirds of those needing palliative care live but enough resources are not available.
- 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. Hospitals are meant for care of acute, not chronic illnesses. It is only the community that can support these needs.
- With more people living in cities and joint families becoming less common, the traditional social support is no longer available, adding to the difficulty.

Team Work

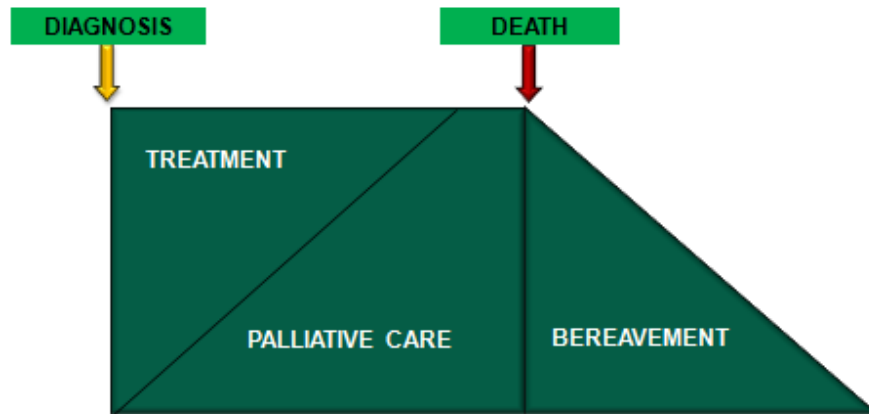
- Palliative care requires a team with many people. It requires various specialists working with palliative care physicians, nurses, social workers, spiritual care guides, community health workers, physiotherapists as well as the patient's family.
- There is a huge need for palliative care in India. Out of the 7 million people who die every year, almost 4 million need palliative care but less than 1% are able to get it.
- 2/3rd cancer patients are incurable by the time they reach the hospital and have severe pain.
- Most HIV/AIDS, kidney and heart failure patients also have moderate to severe pain.
- Sadly less than 4% of patients in India get proper pain relief.
- These patients may also have nausea, vomiting, constipation, breathlessness, smelly wounds, lack of sleep and hunger, tiredness, weight loss, worry about change in the body and looks, sexual problems, loneliness, worry, anger, sadness, anxiety, 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 is palliative care available?

- 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 patients are more comfortable in their own home. It is cheaper and the family can take care without having to travel or lose out on employment.
- Palliative care can be provided at small primary health centres, secondary level hospitals or the referral hospitals, along with the patient's regular treatment.
- It should be a part of existing healthcare at all levels of care. Low cost, effective palliative care can be delivered as part of primary care even in far-off areas.
- Most of the palliative care is required in the community and can be provided in villages by training doctors, nurses, community health workers, volunteers and family members. Some patients with difficult symptoms may need to be referred for specialist palliative care.

Early palliative care gives the best results

- Palliative care should be started early, preferably from the time of diagnosis.
- This helps build trust, plan ahead to prevent symptoms and have timely discussions with the family.
- It helps plan for good end of life care by making wise, well-informed and timely decisions when the disease is advanced.
- 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 near death, 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
 - Referral for palliative care
 - Guiding families for care at home
 - Acting as a link between the patient, the family and the palliative team
 - Help create awareness and change the wrong beliefs
 - Create awareness about various benefits and welfare schemes provided by the government.

Chapter 2: Basic Skills Required for a Community Health Worker

Basic Skills of a Community Health Worker

- The people in the community who suffer from chronic, incurable illnesses or are bedridden face problems in day to day living as well as health care.
- They are emotionally upset, socially isolated, have to depend on others for care and survival. Hospitals often feel that 'there is nothing more to be done' and send them away.
- These patients can get good quality palliative care through primary health care and home care. This needs the support of the people and the community.
- The Community Health Care Worker (CHW) is the most important person linking up the patient, community and health institutions.

The aim of care is to:

- Cure if possible
- Decrease pain and suffering
- Ensure early identification and prevention of disease conditions

The basic principles to be followed while caring:

- Safety of the patient and the carer
- Effectiveness of the interventions
- Comfort, both physical and psychological
- Fair use of resources
- Adequate knowledge and skills
- Treatment to be individualized.

To be effective, a community health worker (CHW) should have the following skills:

1. Communication skills

- Active Listening – This is different from hearing. It is important to understand what is said by patients, families, colleagues. If not able to understand, ask and clarify. Do not assume things.
- The CHWs should be able to speak clearly so that information is effectively conveyed.
- They should be able to read and write clearly.

2. Recognise who needs help

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

3. Provide assessment and guidance

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

4. Facilitate referrals/networking:

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

5. Working with the community

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

6. Capacity building

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

7. Special skills

Other desirable skills are:

- **Leadership skills:** They should have credibility within the community, be a role model to others and be able to mobilise resources and people from the community.
- **Management skills:**
 - The CHWs should be able to organise the National programme activities at their level. Eg planning events and time tables, getting supplies and preparing reports.
 - They should know how to document the problems and reports.
 - They should act as advocates for palliative care and for their patients and should raise their problems at appropriate forums.
 - The CHWs should evaluate their services from time to time and take part in surveys and data collection.

The following steps are suggested while visiting people at home:

- Know the patient and family well. Even if you know them, cross check beforehand the names, the disease and socio-cultural status.

- If on a follow-up visit, check the problems they had, the management planned and anything that the care team had to take care of.
- Address the patient and family respectfully.
- Introduce yourself and the team members.
- Explain the purpose of the visit.
- Try to start a friendly conversation.
- If there are forms to fill, it can be done later during the visit.
- Listen actively.
- Ask about social, emotional, financial and spiritual problems. You may start from the most distressing issue and move on to the others.
- The patient and family may not share all their feelings during the first visit but may do so later. If they do not want or are uncomfortable discussing a certain topic, do not force them. You can discuss these issues later when a good rapport is built.
- Allow them to ask questions. If you are not very sure about the answers, say so. You may discuss with others before answering.
- Discuss with appropriate persons and experts in the team if needed. Clearly explain the management plan to the patient and the carer.
- Do the necessary and appropriate interventions.
- Document your visit, the information gathered and the procedure done.
- An abridged version of the initial assessment format which can be used for documenting the follow up visits is annexed.
- Plan further follow-up if required and date for next visit. Communicate this to the patient and family.

Chapter 3: Communication Skills

Communication is exchange of ideas or feelings between two or more people. Communication is important for understanding the problems of the patient and family and deciding on management. Good communication can help in the patients' and families' psychosocial problems. Communication can be verbal or non-verbal. More than 70% of communication is non-verbal. It should be a two-way dialogue, not one-way.

Why do we communicate?

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

Good communication can:

- Reduce uncertainty
- Improve relationship
- Prevent unrealistic hope
- Allow appropriate adjustment
- Provide personal satisfaction
- Guide and give direction to patient and family
- Ensure compliance

Result of poor communication:

- Mistrust
- Unrealistic expectations
- Patients do not get an opportunity to complete unfinished work in life
- Increased patient distress and anger
- Lack of co-operation and increasing demands from the patient

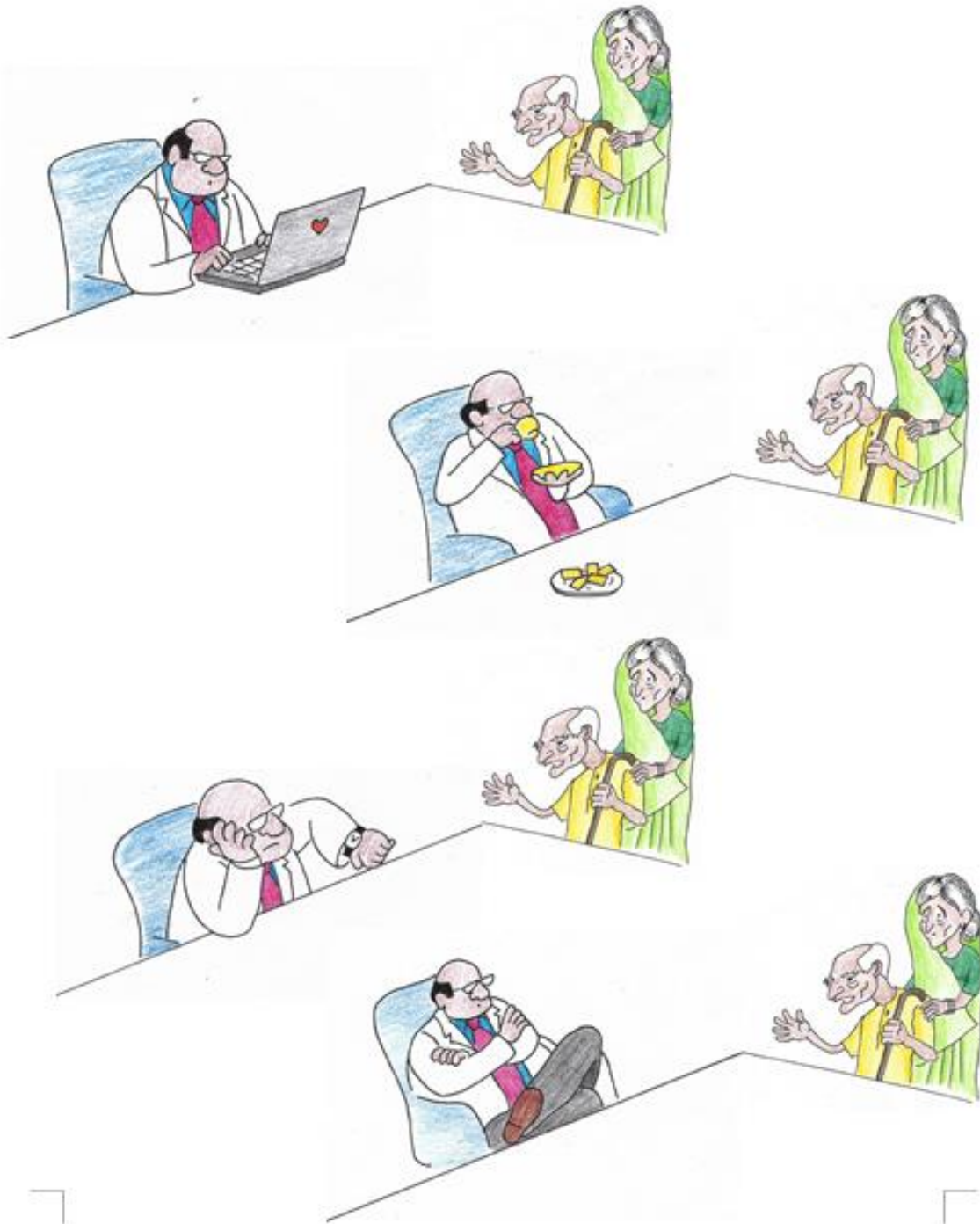
Barriers in communication

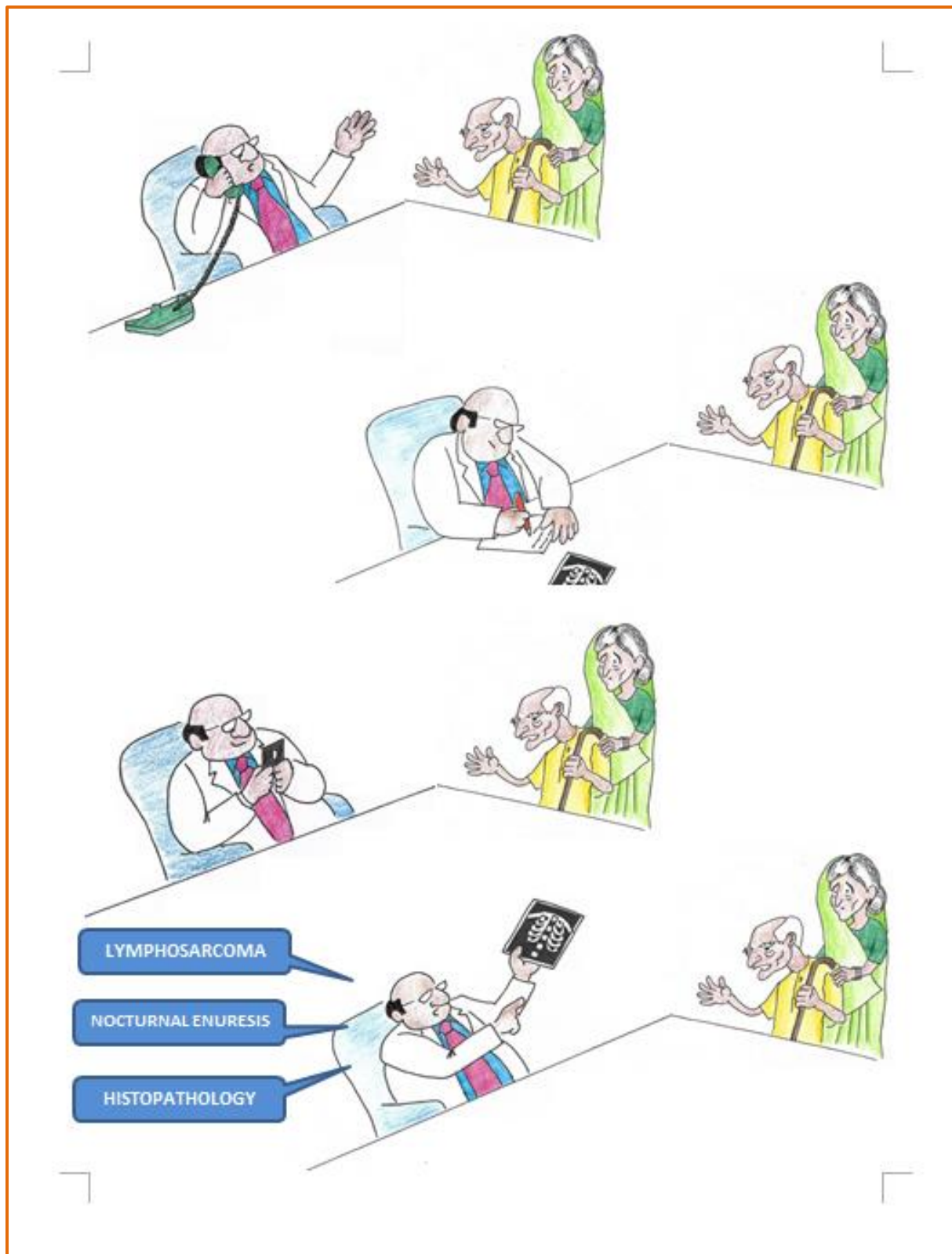
- Fear of upsetting the patient
- Fear of causing more harm than good
- Unsure about answering difficult questions.
- Afraid of saying "I don't know".
- Unable to handle patient's emotions.
- Unable to improve the situation.
- Fear of being blamed.
- Lack of common language.
- Lack of time.

Problems in patient's communicating:

- They think we are busy
- We ask only about physical issues, not about their emotional problems
- They are afraid that they will not be able to control their emotions
- They are afraid of the truth.
- They cannot understand medical terms.

BARRIERS TO COMMUNICATION





Barriers to good communication:

- Pretending to be busy
- Premature/false reassurance
- Talking only about physical issues
- Avoiding stressful situations

- Patronizing and talking down to patients

Basics steps of communication

- Preparation
- Questioning
- Active Listening
- Responding

Preparing to listen:

- Introduce yourself
- Sit down
- Get physical objects out of the way

Non-verbal communication:

- Maintain eye contact
- Posture- lean forward attentively. Don't tap your feet or twiddle thumbs.
- Facial expression, tone of voice should match the patient's
- Reassuring touch, if appropriate.
- Ask open questions - encourage the patients to talk about the problems.

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. Note the emotional tone when patient communicates (non verbal & verbal)
6. Find out about the patients' issues.
7. Willingness to know about the treatment.
8. Discuss with the patient what the patient wants to know.

Responding

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

Planning the follow-up

- Understand patient's problems and what is most important for them
- Make a care plan
- Explain the plan
- Prepare for the worst while hoping for the best.
- Identify other support sources and include them in summary.
- Summarize

General points:

- Talk less, listen more.
- Encourage the patient to talk.
- Remove distractions like mobile phone.
- Be patient, tolerate silences

- Hold your temper
- Don't argue or criticize
- Ask questions to clarify and check understanding
- Do not interrupt unnecessarily.
- Acknowledge emotions.

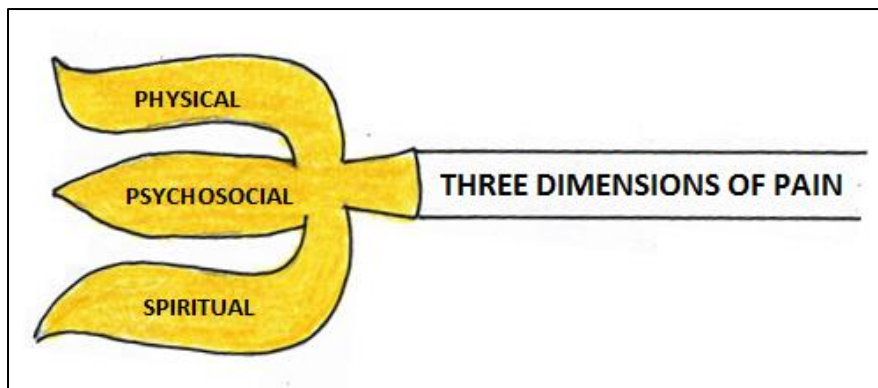
Chapter 4: Management of symptoms

4.1: Pain

Definition of Pain:

“Pain is an unpleasant experience because of actual or likely damage to tissues. It is subjective and varies from person to person. It is both a physical and an emotional.

It has three dimensions- physical, psycho-social and spiritual. This concept is called – ‘Total pain’. Without taking care of each part, we cannot treat pain properly.



Any pain that lasts more than three months is called chronic pain. Chronic pain causes permanent changes in the nerves, so the treatment is different from that of acute pain.

Acute pain like that of injury and surgery causes patients to cry with pain or roll around. It decreases with time as healing takes place. It is treated with as and when needed injections or tablets.

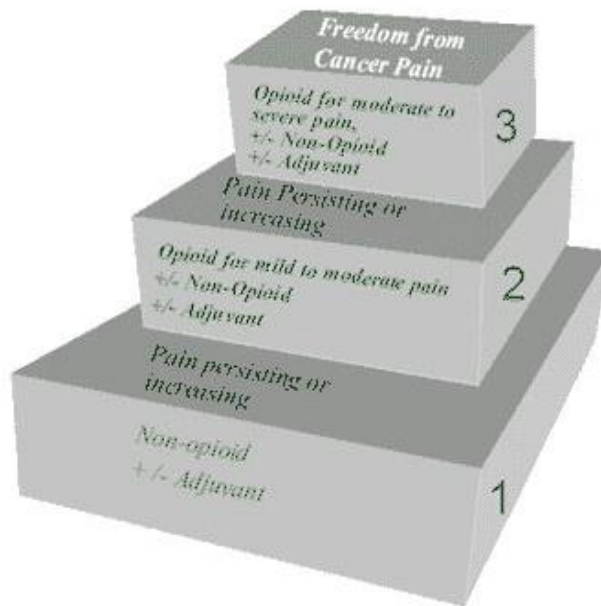
Chronic pain however, does not decrease with time. It increases as the disease advances. However, the patient may not cry or even look like he is in pain. He becomes quiet, withdrawn, loses appetite and sleep and may lie quietly in a corner, not talking to anyone.

This pain is not treated SOS or with injections. This needs oral, round the clock medication in doses enough to make him pain-free. A combination of medicines may be needed. As the disease advances, the patient may need increased doses or more medicines. This does not mean that he has become addicted.

The World Health Organization has given guidelines for cancer pain management- called the ‘WHO Pain Ladder’ that can also be used in other cases. It has three steps.

- STEP I - (For mild pain): Medicines used are- Non-steroidal anti-inflammatory drugs- eg. Paracetamol, Diclofenac or ibuprofen.
- STEP II – (For moderate pain): Weak opioids: eg Codeine, Tramadol
- STEP III – (For severe pain): Strong Opioids: Morphine, Fentanyl, Buprenorphine, Methadone.

WHO's Pain Relief Ladder



Source : <http://www.who.int/cancer/palliative/painladder/en/>

Adjuvant analgesics (Co-analgesics)

These drugs are mainly used for some other purpose but can help control pain. eg Antacids for pain due to acidity and anti-anxiety drugs when sleeplessness due to anxiety is increasing pain.

One can go both up and down the ladder ie the medicines can be increased and decreased too. Patients may not permanently require a particular medicine.

Note: Once the patient is started on pain medicines, it is very important to review them regularly to find out the exact dose needed and to check for side effects.

Medicines for chronic pain must be given:

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

Morphine remains the gold standard for treatment of severe pain. It is a safe drug if used by trained personnel. However, it needs to be used carefully and patients must be under supervision. It can be in the form of injections, tablets, suspension or rectal suppository. Oral morphine in the form of tablet or syrup is preferred for chronic cancer pain. It is not the first choice for chronic, non -cancer pain.

Basics of morphine use:

- There is no standard dose or upper limit for chronic cancer pain, correct dose is that which controls pain with minimal side effects
- Dose is to be titrated for each individual patient.

- A laxative and anti-emetic for constipation and nausea/vomiting must always be given with morphine.

Myths about morphine:

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

Side-effects of morphine:

- **Constipation - Laxative must always be used in correct dose**
- Nausea/vomiting - metoclopramide, domperidone, haloperidol can be given
- Urinary retention
- Itch/rash - antihistamines, are not very helpful.
- Dry mouth- give sips of water frequently.
- Respiratory depression – uncommon when titrated properly
- Neurotoxicity- can have muscle jerks rarely

Prescriptions for morphine require:

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
4. Name and registration number of doctor
5. Three copies are needed- for patient, doctor and chemist/ pharmacy

Non-pharmacological (non-drug) methods-

These are non-drug methods to help control pain. Physiotherapy, hot and cold packs, massage,

Proper positioning, reassurance, diversion therapy, art or music therapy, acupressure and acupuncture can help.

4.2: Breathlessness

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

Management:

1. Some causes are reversible. Eg wheezing due to tightening of airways. It can be made better with medicines given by the doctor. Check if the patient has been given any drugs or nebulizer earlier
2. Morphine is very helpful in decreasing breathlessness by acting on various centres in the brain.

3. Oxygen: may help in few cases where there is less oxygen in the blood but in cases where the lungs are destroyed by the disease, it may not help.

4. Non-pharmacological (non-drug) treatment-

This is very important treatment modality, and the family should be taught about this.

These include:

- Propping up with pillows or cushions
- Putting a fan near the patient to direct a stream of air over the face
- Good ventilation by keeping doors and windows open
- Placing the patient near an open window
- Calm environment
- Loose, comfortable clothes
- Wiping the face with a wet towel
- Rubbing the back
- Relaxation techniques- asking the patient to think about something pleasant eg. a favourite holiday spot, happy memories, favourite songs, thinking about a calm scene like a sea shore/ mountain etc.
- Physiotherapy in the form of deep breathing, leaning forward and pursed lip breathing
- Talking to the patient in a calm and soothing voice
- Discussing their fears openly
- The family should keep calm and not panic because anxiety spreads quickly from one member to another.

NON PHARMACOLOGICAL MANAGEMENT OF BREATHLESSNESS



Breathlessness in a dying patient

Patients often fear suffocating to death. No patient should die with distressing breathlessness. There are medicines which can help prevent and treat breathlessness in the dying. It is good to plan for future steps in case the patient has advanced illness. The family should be advised on emergency medicines available with help from the palliative team. Call or refer to the doctor for advice.

4.3: Nausea and Vomiting

“Nausea is an unpleasant feeling of the need to vomit and “vomiting is the forceful throwing out of stomach contents through the mouth”. Nausea causes more misery than vomiting.

Management

Non-pharmacological (non-drug) management:

- A calm, reassuring environment away from the sight and smell of food
- Avoid exposure to foods, which precipitate nausea
- Small frequent meal
- Cold food is tolerated better than hot food
- Control of bad smell from wound.

Pharmacological (drug management)

Always give anti-emetics regularly, not SOS. If vomiting is continuous, try to avoid oral medications and consult the doctor. Morphine in the starting days can cause nausea and vomiting which can be controlled with drugs. Different causes of vomiting need different medicines and sometimes a combination may be needed. Consult the doctor or nurse for help.

4.4: Constipation

Constipation is the difficult or painful passing of stools, less number of stools which are hard. About 45% of palliative care patients are constipated. It can cause 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, low fibre diet
- Poor fluid intake or increased fluid loss (vomiting, diarrhoea)
- Inability to raise intra-abdominal pressure (general weakness, paraplegia)
- Inability to reach toilet in time
- Opioids (90% of patients taking opioids need laxatives)
- Embarrassment in public place
- Pain (fissure in ano)

Management

Non-pharmacological (non-drug) management:

- Being able to get to the toilet may be more important than laxatives
- Timing and privacy
- Straining damages pelvic muscles
- A squatting position helps
- As far as possible patients should be encouraged to eat a normal balanced diet and drink plenty of fluid, but this may not be possible in palliative care patients.

Drug management for severe constipation - Consult the doctor

4.5: Diarrhoea

Diarrhoea is defined as the passage of more than three loose stools in 24 hours. Patients can understand “diarrhoea” in different ways so always clarify. Diarrhoea is less common than constipation in patients requiring palliative care.

The common causes of diarrhoea in the palliative care setting:

- **Imbalance** of laxative therapy - commonest cause.
- **Drugs** (antibiotics, pain medications)
- **Faecal impaction** may be due to fluid stool which leaks past a faecal plug or a tumour mass (“overflow diarrhoea”)
- **Change in diet**

General Measures

- Increase fluid intake- frequent sipping of water/ Home-made ORS/ Daal water/ Lemon water/ Coconut water
- Reassurance that most diarrhoea is self-limiting.

For specific drug treatment - consult the doctor

Chapter 5: Nursing issues

5.1: Care of the bed ridden patient

Nursing care of bed ridden patients is quite challenging Patient may be conscious or unconscious.

In a bedridden patient, the care includes:

- Health education of the family.
- Involving the family in the care.
- Demonstrate the care and make a follow up plan.
- Regular home visits.
- Airway clearance
- Adequate fluid intake (oral, nasogastric tube feeding)
- Bowel and bladder care
- Personal hygiene- head to foot care
- Prevention and care of pressure sores
- Exercise
- Communication
- Assessment of symptoms, recording and reporting.

5.1.1: Care of hair and how to give head bath

Stimulating the scalp by massage and brushing improves circulation and keeps 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.

5.1.2: Care of eyes

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

5.1.3: Care of nose and ears

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

Dirt may accumulate behind the ears and in the front part of the 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, refer to ENT surgeon.

5.1.4: Mouth care

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

5.2: Care of dependent patients:

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

5.2.1: Assisted oral care

- Explain the procedure to the patients and help them.
- Assemble the things needed for mouth care ie toothbrush, toothpaste, small basin, water in a jug, towel, lip lubricant.
- (Needs demonstration)
- Put him on side lying position with a towel below the cheek.
- Cut short the bristles of the toothbrush and wrap with the gauze or sterile cotton cloth.
- Use Soda bicarbonate 1 tsp in one pint of water.
- Or one tsp of salt in 500ml of water and boiled
- Remove all the water from the mouth to prevent aspiration.
(Demonstration.)

5.2.2: Bed bath

Bathing is very important in maintaining and promoting hygiene. It helps:

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

General instructions for bed bath

- Maintain privacy.
- Explain the procedure.
- Patient's room should be warm and free of draughts.
- All needed equipment should be at hand and conveniently placed.
- Avoid giving unnecessary exertion to the patient.
- Remove the soap completely from the body to avoid the drying effect.
- Only 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.
- 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.

5.2.3: Back care

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

5.2.4: Nutrition – oral intake or naso-gastric feeding

The patient and family must be educated about the importance of nutrition.

General instructions –

- Diet must be planned according to the needs of patient.
- 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.
- Give easily digestible food
- Give time to the patient to eat the food.
- Talking to the patient while he/she is eating will make the patient feel good.
- Before and after food give water for hand washing and oral care.

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

- Give the patient 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 prevent aspiration)
- Give 2 hourly feed and after 10 pm (night) just two feeds at 3 hours interval.
- Prepare feed at home with what is available like vegetable and daal soups, milk, water, fruit juice, rice cooked water.
- Before giving the feed, strain and then give the food.

5.2.5: 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.

5.2.6: Care of perineum

Perineum should be cleaned after each act of urination and defecation. Clean with soap and water daily 3 to 4 times and keep the area dry. Clean from the cleanest to the less clean area. The urethral orifice is considered as the cleanest area and the anal orifice is considered as the least clean area. Hands should be cleaned after giving perineal care.

5.2.7: 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 massage for painful areas, if possible.
- Give hot water fomentation on lower abdomen or a wash with warm water.
- Stimulation by seating patient next to running water.
- Patient should be given enough time to empty bladder completely

Patient with an indwelling catheter needs:

- Cleaning from the umbilicus to mid-thigh daily once.
- Cleaning the vulval area and catheter 2 or 3 times daily with soap and water.
- Foley's catheter has to be changed every 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 3/4th full.
- Observe if urine is draining freely
- Secure the urobag below the waist or leg while walking.
- Observe the colour and amount of urine.

5.3.7: Condom catheter

Needs to be considered when all other options fail/cannot be applied. Patients are usually provided with two condom catheters. It must be removed, cleaned and changed twice daily. Catheters can be used 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.

5.3.8: 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 insufficient blood flow and necrosis of the area.

Purpose of care

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

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

2. Relieve the pressure

- Reposition every 2 hours
- Do not rest on hip bone directly.
- Avoid elevation of 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. 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.

5.3.9: Bowel Care

Constipation is more common than diarrhoea. Carefully assess bowel function on daily basis. Take a detailed history. Passage of hard stools is difficult and painful. Always compare with the 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. Encourage deep breathing, abdominal massage etc. Encourage intake of fibre rich diet and fluids.

Prevention:

Simple measures should be incorporated as part of the routine plan in all patients.

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

5.4: Malignant wound care

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

Management

- Minimize pain, infection, bleeding, odour and psychological trauma.
- Prevent maggots

- Simple dressing material which can be sterilized in a 'pressure cooker' at home are useful
- Dressing should be comfortable, acceptable, cheap and available locally.
- The simplest products may be the best and the most cost- effective.

Physical problems

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

Psychosocial problems:

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

1. Management of bad smell.

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

2. Management of discharge

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

3. Pain management:

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

4. Management of bleeding:

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

5. Management of Maggots

- If maggots are present, apply or flush plain turpentine 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
- Always keep the wound to prevent maggots.

6. Management of Infection:

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

7. Patient's comfort

- Use dressings that will be most comfortable to the patient and cost effective.
- Used cotton saris or any soft cloth can be made into gauze pieces and gamgee pads. Coloured pads have the advantage of masking the colour of blood or exudates from wounds.
- Pile up this dressing materials in an idli vessel or 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 add one tsf of salt and boil for 10 minutes.
- 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.
- 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.

5.5: Tracheostomy care

A tracheostomy is an artificial opening made into the trachea into which a tube is inserted to establish and maintain a patent airway.

Parts of a tracheostomy tube

- **Outer tube**

Outer tube held in place by a ribbon or tie which is passed through the loops on either side of the opening of the tube.

- **Inner tube**

Fits inside the outer tube. The inner tube is held in place by a small flip lock which is located on the top part of the outer tube

Complications:

- Accidental expulsion of the tube during coughing
- Infection of the wound and lower respiratory tract

- Choking of the patient due to dropping of food or water into the tracheostomy opening

1. Routine care

- Cleaning inner tube - thorough cleaning of the inner tube should be done with soap and water
- The inner tube to be removed and washed under cold running water. Soak it in a solution of normal saline to soften the secretions. Then clean it with soap and water and 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. It should be changed by trained persons when dirty.

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.

Prevent the entry of water directly in to the stoma while bathing, swimming, and shaving

5.6: Ostomy care

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 because 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.

5.7: Lymphedema management

Lymphoedema is accumulation of fluid under the skin. It can be-

Primary: Congenital

Secondary Lymphoedema: 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 stones of management

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

1. 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 can be taken care 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.

Chapter 6: Psychosocial and Spiritual Support in Palliative Care

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. This is known as empathic communication.

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.

Therefore, 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. 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.

Key points to remember:

- 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, based on 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.

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

1. First, you need to do a self-assessment:

a. 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.)

b. 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 one caste or community over another?

2. 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?
3. 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

Benefits of empathic listening:

- 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 differ, 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

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:

Most 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 prioritise 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 a 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 realise 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. Often what they are asking for is helping 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 recognise 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.

Important points

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.

Chapter 7: End of life care

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

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

Recognizing the terminal phase

Remember, these signs and symptoms are just relative...wide variations can occur, so it is not possible to predict accurately.

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

Goals of care

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

Giving fluid

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

- Discuss risk of aspiration

- Encourage caregivers to give lip and mouth care
- What the patient can be given depends on the level of consciousness, ability to swallow, level of thirst, need for medicines
- Adverse effects of Intravenous fluids
 - Difficult at home
 - Expensive
 - Needs supervision
 - Infection can occur
 - Fluid can collect in the lungs
- **Review**
 - All medicines taken by patient with doctor and find out if any 'non-important' medicines can be stopped
 - The doctor will decide on the best way to give medicines
 - Intramuscular and intra venous routes are avoided
 - Subcutaneous injections can be used
 - Regular review is needed
- **Good symptom control:**
 - Provide '**non-drug**' methods of symptom control
 - Control of pain: continue pain medicines after discussion with doctor.
 - The patient is likely to pass urine and stool in bed. The caregivers should be taught how to clean the patient
 - After discussion with the caregivers and doctor, catheterization may be needed.
 - If the patient cannot swallow, after discussion with the doctor and with 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
 - 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, restlessness and confusion
 - Look for causes like pain
 - Ask the doctor for medication
 - Noisy secretions (death rattle) are due to collected secretions at the back of the throat when patient is too weak to swallow them. They do not cause discomfort to the patient but relatives may be worried that he is choking or in pain.
 - Explain to caregivers that it does not cause distress to the patient
 - Try non-drug measures
 - Position the patient in recovery position.

- Remove the secretion from angle of mouth using finger wrapped in a gauze piece by 'hooking' the finger and 'swiping'
 - Ask the doctor for medication
- Fits
- Prevent the patient from self-harm. Do not force any object like a spoon into the mouth.
- If possible, give intravenous, subcutaneous or intramuscular midazolam or any other drug suggested by the doctor
- Continue anti-epileptics as prescribed
- Severe bleeding
 - Plan for this possibility and discuss with family in advance
 - Apply firm and steady pressure where possible using dark towels or bedsheets
 - Sedate the patient quickly with intravenous, subcutaneous or intramuscular midazolam or any other drug suggested by the doctor
- Supporting the family
 - The family is suffering as much or even more
 - Address religious, social and spiritual needs
 - 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 as they wish
 - Confirming death
 - Wash hands
 - Confirm identity of patient
 - Watch for signs of life like movement, breathing, twitching etc
 - Look for signs of efforts to breathe
 - Does patient respond to verbal stimuli?
 - Does patient respond to pain? (Pressure over eyebrows or sternum)
 - Check for pupil reaction using pen torch...after death they become fixed and dilated
 - Feel for a central pulse (e.g. carotid artery)
 - Listen for heartbeat, if a stethoscope is present
 - Listen for heart sounds for at least 2 minutes
 - Listen for breath 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

Bereavement Support for the family

- Palliative care does not stop with the patient's death. It continues after the death of the patient in the form of bereavement support for the family.
- After the death, pay a bereavement visit to the family.
- Collect back any unused opioids and hand them to the palliative team.
- The family may need support for a few months after death
- People may grieve for six months to one year after death and then slowly resume normal life
- Some people may find it very difficult to accept, especially the death of the earning member or a child and go into depression. They will need referral to a counselor or psychiatrist.

Chapter 8: Community participation in palliative care

Role of Community in Palliative Care

People living with chronic illnesses 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 most, death is preceded by a period of suffering for days, weeks, months or years. The main fears they have are fear of death and abandonment. Most prefer to be cared for in their homes and wish to die at home. There are enough resources available in any community to build a 'safety net' around these patients.

Community Participation

Community is a group of people living together. Community participation is the involvement of people in a community to solve their own problems. Community participation can be of two types:

1. Helping through resources (money, manpower, time etc)
2. Taking responsibility for identifying patients and caring for them

A Kerala based community based palliative care program called Neighbourhood Network in Palliative care (NNPC) is an example of a successful community owned palliative care program.

Benefits of Community Participation

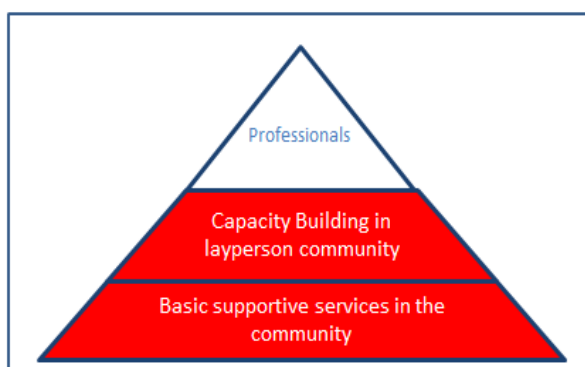
1. The patients and families get health services nearby.
2. The community benefits through improving skills, confidence and empowerment.
3. Awareness and acceptability of palliative care
4. Positive outlook towards incurable diseases.
1. It helps change social and cultural factors
2. It ensures that health services are accountable and provide good quality care.

Two parts of Community Based Palliative Care Program are:

- **Community volunteers**
- **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.



They can be:

1. **Untrained volunteers:**

They help in the 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 motivated volunteers can undergo a formal training in palliative care and get involved in direct patient care, e.g., providing emotional support, basic nursing, help with mobility, managing medicines etc.

Role of community volunteers:

They can provide -

- Emotional support
- Basic nursing care
- Linking up with the professional team
- Social support through giving-
 - Food for the family
 - Educational support for children
 - Helping with transport to hospital
 - Linking with other support groups and benefits from government / NGOs
- Rehabilitation
 - Community volunteers can take up responsibilities related to:
 - awareness programmes
 - Training the family members to look after the patient
 - Training volunteers
 - Administration of the unit
 - Fund raising

Health Care Professionals

Most health care professionals in the team are paid. This team can be helped by additional voluntary efforts from other health care professionals. A community level care should have a good link with a primary, secondary and tertiary health care system for any referral.

Role of Community Health Worker (CHW)

CHWs are members of the community they serve and serve as an important link between the community and the patient and family.

Role of family

Family and friends are very important in providing round-the-clock care to patients in their homes. The health care providers can empower the family by education and training so that they can look after the patients with help from the volunteers.

How to mobilise a community?

It means encouraging and motivating the people. Creating awareness is the first step. Repeated meetings with self-help groups, organisations of women and elderly citizens, village administration, schools, involvement in festival and religious gathering etc are helpful. It is important to ensure that minority groups, low status groups and poorer groups in the community are not left out.

Fund generation

A fund generating activity may be an important starting point to make communities responsible. Micro funding through small donations can be undertaken, by placing donation boxes at public places, collections from student community, donations of cash and kind during festive

occasions etc. Helping the patient and families to earn by setting up a small groceries or vegetable shop, tailoring, haircutting saloon etc all help.

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 include it into the main health policy eg in Kerala