

Training Manual on Palliative Care for ASHA at Ayushman Bharat – Health and Wellness Centres













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Preamble

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

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

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

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

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

And palliative care is not only for the patient but also for the family, and therefore even when the patient dies, psycho-social support may have to be continued for the bereaved family.

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

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Introduction to the module

India is currently in phase of epidemiological transition and has to deal with the double burden of Communicable and Non-Communicable diseases [NCD]. Currently NCDs contribute to about 2/3rd of mortality in our country. However, the public health system of our country is predominantly directed towards dealing with the communicable diseases. This changing health scenario has been recognized by the National Health Policy-2017. The policy envisages to "Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality". This was further emphasized in the concept of comprehensive primary health care in the Ayushman Bharat Yojana. The expanded list services related to NCDs and Palliative Care will be provided through the Health and Wellness Centres [HWC].

Palliative care is required for patients with a wide range of life-limiting health problems. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Patients with many other conditions may require palliative care, including kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

ASHA & Multipurpose Health Worker (Female/Male) have been recognized as the frontline workers for community outreach activities of Health & Wellness Centre. The addition of palliative care as part of comprehensive primary health care represents the inclusion of a new sub-population group into the activities of the HWC. This requires orientation, sensitization and learning from experiences with implementation across states. To ensure that the training of ASHA is in alignment of the expected role, following set of competencies have been identified.

Suggested Palliative Care Related Competencies for ASHA

- Demonstrates an understanding that palliative care addresses all aspects of health-related suffering of both patients and families.
- Demonstrates an understanding and application of the principles of good communication in palliative care.
- Demonstrate the basic assessment of patients/families to identify their palliative care needs using the assessment tool provided.
- Demonstrate the ability to organize home care visit.
- Demonstrate an awareness about the common medications used in Palliative Care including essential opioids.
- Demonstrates an awareness of the common issues associated with death and dying, and understands various ways of responding to them, including the bereavement support.
- Demonstrates an understanding of the roles, responsibilities, scope and limitation of ASHA in context of providing Palliative care to the communities.
- Demonstrates an understanding of the palliative care service available through various national health programmes.
- Demonstrates an awareness of the social support system and organizations working for social issues in the communities.
- Describe the importance of community participation in delivering effective palliative care

Chapter 1: Introduction to Palliative Care

Competency: Demonstrates an understanding that palliative care addresses all aspects of health related suffering of both patients and families

Specific Learning Objectives

- Describe brief history of palliative care
- Define Palliative care
- Enumerate domain of sufferings with examples
- Enumerate 5 important principles of palliative care
- Describe the current situation of Palliative care in India/ local state
- Describe the concept of Palliative care as part of a continuum of care
- Describe the interface between palliative care and primary health care

Activity 1:

Ms. Savitri is a 32-year-old lady with advanced breast cancer in your neighbourhood. She has two children aged 8 and 6. Her husband is a manual labourer. The treating doctor has told the husband that her disease is not responding to treatment and the patient is likely to die in 6–9 months. You visited her yesterday. She complained of pain all over the body. She looked very worried. As a neighbour, what can you do to help this patient and her family? Who all can you seek help from?

Adapted from: Palliative Care- A workbook for Carers, Institute of Palliative Medicine, Calicut.

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.
- Palliativecare:
 - 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 of Palliative care in India

- In the olden days, in India, there were places built where the dying was 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 theworld.
- Palliative care units in started in 1980s. Most of the palliative care centres in India are located in the South, especially Kerala where community involvement has been the outstanding factor.

National Programme for Palliative Care was launched in India in 2012. National Health Policy [2017] also recognizes palliative care as an integral part of comprehensive primary health care.

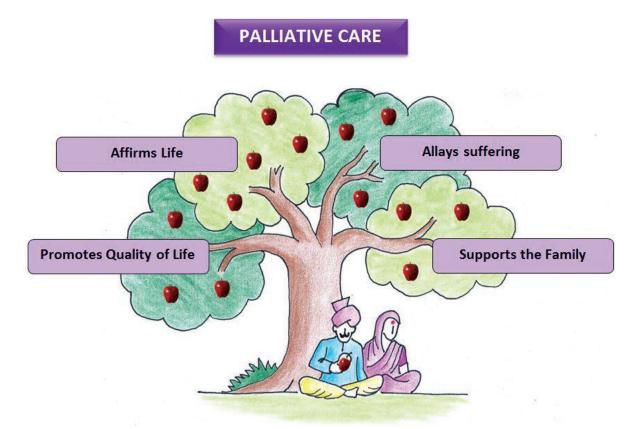


Figure: 1- Components of Palliative Care [Source: Handbook for Health Care Workers, National Programme for Palliative Care

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
- Stroke or spinal cordinjuries
- Old age conditions like Alzheimer's disease etc.
- Children with cerebral palsy or birth defects etc.

The principles of palliative care [Figure 2]:

- Patient & Family is at the centre of the 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.

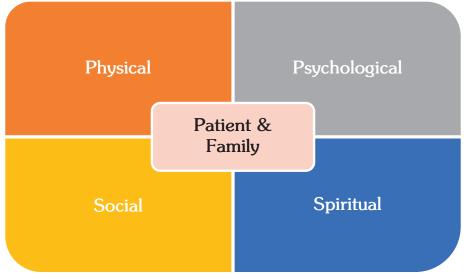


Figure 2- The principles of palliative care

What is the need for Palliative Care?

- Out of the need 7 million people who die every year, almost 4 million need palliative care but less than 1% are able to access it
- With changing lifestyle, non-communicable 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.
- 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. Current health care system is mostly 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.

Who are the members of Palliative Care Team?

• Palliative care requires a team approach. It requires various specialists working with palliative care physicians, nurses, social workers, spiritual care guides, community health workers, physio therapists as well as the patient's family. Community based volunteers, health workers are very important members of this team.

Where are palliative Care Services provided?

• Palliative care can be given any where - at home, in the hospital or in a place for the terminally sick which is called a 'hospice'.

Free standing hospices

Inpatient care in general setting

Outpatient care

Home based

Figure 3: Access to palliative care services

- In India, home care 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 health care at all levels of care. Low cost, effective palliative care can be delivered as part of primary care even in far-offareas.
- 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.

When to initiate Palliative Care Services?

- > To yield 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 thefamily
- It helps plan for good end of life care by making wise, well-informed and timely decisions when the disease is advanced.

Chapter 2: Communication Skills

Competency: Demonstrates an understanding and application of the principles of good communication in palliative care

Specific Learning Objectives

- Describe the importance of communication in health care
- Describe the components of communication
- Enumerate types of communications
- Enumerate barriers in communication [Patient/ Health care Worker]
- Describe the implications of poor & good communication
- Describe important principles of good communication
- Demonstrate the steps of communication
- Enumerate 5 important 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

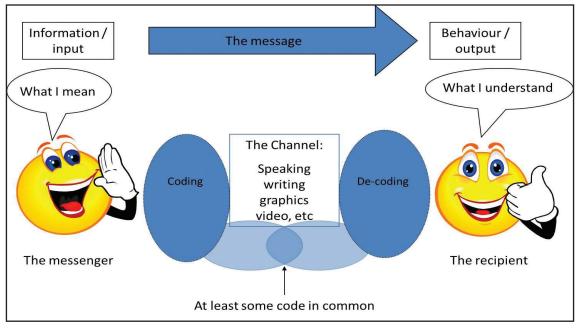


Figure 4: Process of Communication

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

What are the benefits of good communication?

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

What are the 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

What are the barriers in communication?

- Fear of up setting 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

What are the problems in patient's communication?

- 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

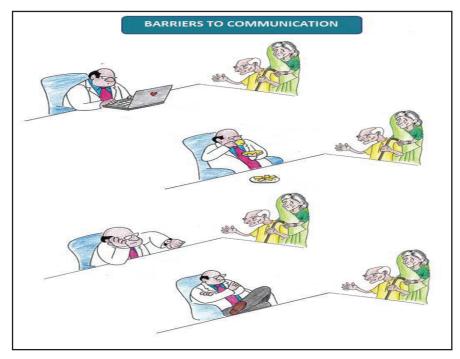


Figure 5.1: Barriers to communication (Source: Handbook for Health Care Workers, National Programme for Palliative Care)

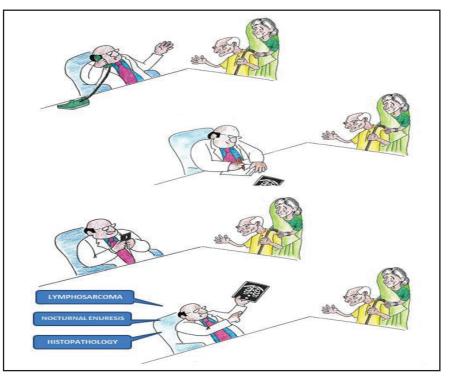


Figure 5.2 Barriers of Communication

What are the basics steps of communication?

- Preparation
- Questioning
- Active Listening
- Responding

What are 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 patient's emotional tone (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

How to respond at the end of the communication?

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

What are the steps for planning 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

Key Points to remember:

- 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

Chapter 3: Management of symptoms

Competency: Demonstrate an awareness about the common medications used in Palliative Care including essential opioids

Demonstrate an awareness about the role of non-pharma cological interventions in Palliative Care including essential opioids

Specific Learning Objectives

- Enumerate common medications used in home care including opioids
- Describe non-pharmacological interventions for management of common symptoms [Pain, Nausea & Vomiting, breath lessness, constipation]
- Enumerate common adverse effects of Morphine
- Enumerate advice to be given to a patient [and their family] who is on Morphine

3.1: 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.

What are the dimensions of Pain?

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

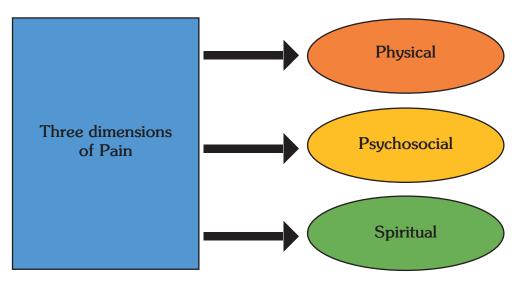


Figure 6: Dimensions of pain

What are acute and chronic 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 tablets or injections when needed.
- 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.

- 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, with drawn, loses appetite and sleep and may lie quietly in a corner, not talking to any one.
- 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.

What are the non-pharmacological (non-drug) methods to manage symptoms?

These are non-drug methods to help control pain

- > Physiotherapy, hot and cold packs and massage
- Proper positioning, reassurance, diversion therapy, art or music therapy, acupressure and acupuncture can help.

3.2: 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. 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.
 - 2. 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.
 - Physio therapy 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



Figure 7: Non pharma cological 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.

3.3: 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

3.4: 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, over flow diarrhoea and urinary retention. Causes of constipation include:
 - 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 on time
- Opioids (90% of patients taking opioids need laxatives)
- Embarrassment in public place
- Pain (fissure in anal area)

> 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

For Drug management for severe constipation – Consult the doctor

3.5: Diarrhea

- Diarrhea is defined as the passage of three or more loose stools in 24 hours. Patients can understand "diarrhea" in different ways so always clarify. Diarrhea is less common than constipation in patients requiring palliative care.
- General Measures
 - Increase fluid intake-frequent sipping of water / Home-made ORS / Dal water / Lemon water/ Coconut water
 - Reassurance that most diarrhoea is self-limiting

For specific drug treatment - consult the doctor

Chapter 4: Basic Nursing Skills

Competency: Demonstrate and understanding of basic nursing care and procedures in home care setting which can be taught to care givers

Specific Learning Objectives

- List key universal precautions to be followed during caring for the patient
- Demonstrate steps of hand washing in a simulated setting
- Describe the steps of bed making
- Describe the method for preparing saline at home
- Describe the techniques for sterilizing supplies at home
- Describe the key issues to be addressed while caring for a bed ridden patient
- Describe the steps for prevention of bed sores
- Describe the management of fungating wound in home care setting

4.1: Care of the bed ridden patient

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

In a bed ridden patient, the care includes:

- Health education of the family
- Involving the family in the care
- Demonstrate the care and make a follow up plan
- Regular home visits
- Airway clearance
- Adequate fluid intake (oral, naso gastric 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

4.1.1: 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 [rubber/plastic sheet]
- 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 herback
- Patients may be advised short clipping of hair if it's acceptable.

4.1.2: 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

4.1.3: 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 removed and if not refer, to ENT surgeon.

4.1.4: Mouthcare

- If the patient is conscious, help the patient in his/her mouth care. If the patient is unconscious, the care givers need to be taught mouth care by demonstrating the procedure.
- Solutions which can be used are Normal Saline, 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.

4.2: Care of dependent patients:

- Two or Four 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 glycerin as it causes dry mouth

4.2.1: Assisted oralcare

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

4.2.2: 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

4.2.3: Backcare

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

4.2.4: 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 stiff ness. If there is no restriction or bone problems exercise can be given by the patient's family.

4.2.5: Care of perineum

Perineum should be cleaned after each act of urination and defection. 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.

4.2.6: Pressuresores

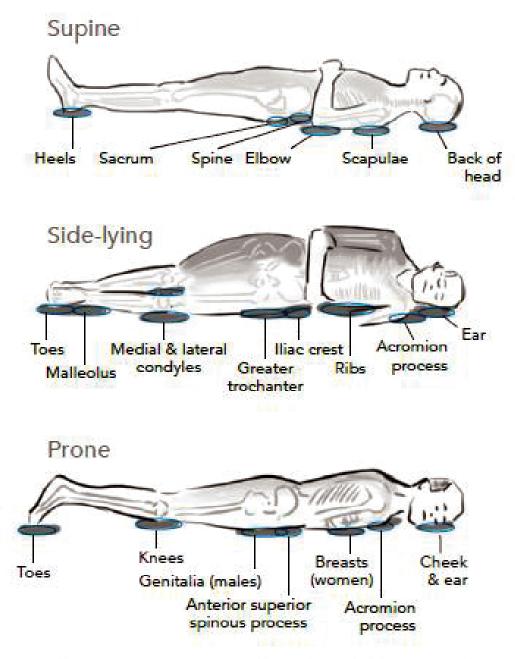
A pressure sore or pressure ulcer is an injury to the skin and tissue under neath, usually caused by unrelieved pressure. Pressure on a small area of the body can compress tiny blood vessels that normally supply tissue with oxygen and nutrients resulting in in sufficient blood flow and necrosis of the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

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 sub cutaneous tissues
- 4. Breakdown of bone, muscle and supporting tissues: This involves deep wounds that are difficult to heal

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.



Pressure Points over Bony Points in Different Lying Postures

Figure 8: Pressure Points in different lying Postures, Source: Palliative Care- A Work Book for Carer's, Institute of Palliative Medicine, Calicut. Measures to prevent pressure sores are provided in the diagram below:

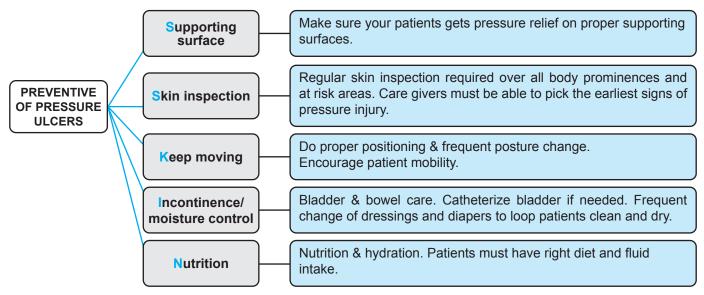


Figure 9: Preventive measures for Pressure ulcers, Source: Palliative Care- A Work Book for Carers, Institute of Palliative Medicine, Calicut.

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

Points to remember

- Maintain daily hygiene with sponge bath, shower, hair care, and shave, trim nails
- Maintain hygienic environment, such as clean clothing, and bedlinen
- Assess skin integrity, especially pressure points,
- 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 water bed or air mattress
- Education of family about care procedures

4.2.7: 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 aspossible.
- Maintain adequate oral fluid intake.
- Use of bed pans: It is mandatory to maintain patients' privacy and use of a commode or lavatory for defecation.

4.2.8 Bed Making

Purpose

- To provide comfort for patients whose physical conditions confines them to bed and for patients on imposed bed rest for the therapeutic reasons
- To change wet/soiled linen for the bed ridden patients
- To maintain neat appearance and clean environment
- To provide a smooth wrinkle free bed foundation thus minimizing sources of skin irritation

Procedure

- Wash hands
- Remove extra pillows
- Loosen the top bedding from head end to foot end. Remove blanket leaving the top sheet over the patient.
- Position the patient on side on the far side of the bed facing away. Adjust the pillow under the head.
- Loosen bottom linen from head end to foot end on both sides
- Clean and roll the mackintosh towards the patient
- Fan fold the bottom sheet towards the patient and push it as close to the patient as possible
- Dust the mattress with dry duster
- Apply clean bottom linen, which is fan folded length wise to the exposed half of the bed, keeping the center fold in the center of the bed
- Fan-fold the bottom sheet towards the patient. Smoothen the bottom layer over the mattress and bring the edge over near side. Allow the sheets to hang about 25 cm over mattress edge, make mitered corner at the head end of the bed. Tuck the hanging sheets on the sides till the foot end. The lower hem of the bottom should be even with the bottom edge of mattress.

- Bring the mackintosh back into place and clean it using dry duster (if soiled replace the mackintosh)
- Keep a pillow in the working side to ensure that the patient doesn't fall and go to the other side
- Loosen the edges of the soiled linen from under neath the mattress
- Remove the bottom sheet. Clean and roll mackintosh towards the patient.
- Dust the mattress and spread the fan folded clean linen smoothly over the edge of the mattress from head end to foot end.
- Pull taut and secure bottom sheet under head of the mattress. Pull the side of the sheet taut and tuck under side of the mattress.
- Assist the patient in rolling back to supine position and reposition the pillow
- Change the pillow cover if required
- Patients with respiratory and cardiac disorders may be unable to tolerate lying flat during bed making. Top to bottom method of occupied bed making can be used for such patients.

Chapter 5: Home Care

Competency: Demonstrate the ability to undertake home care visit

Specific Learning Objectives

- Describe the concept of home care
- Enumerate the contents of home care kit
- Enlist the criteria to identify patients/families who need home care
- Enumerate Do's and Don'ts during home care visit
- Describe role of neighbours/volunteers in home care
- Document home care visit using suitable format
- Demonstrate the steps of communication

Activity 2:

Recall the story of Ms. Savitri. She cannot go to a hospital as her husband is the only earning member of family and he cannot afford to miss job. Also her children are too small to take her to hospital. Can she be provided some care at her own home?

Discuss in small group & share your view

What could be scope of services that can be provided at her home?

Introduction

- End of life Palliative Care patients are mostly bed ridden and cannot come to an OPD of a hospital. Such patients will need to be cared for at a hospice or their homes. Since most of our patients prefer to be cared at homes, home care palliative care services should be provided.
- Home based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence.
- It is also cost effective and as it does not entail travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments.
- Some additional advantages of home care include:
 - 1. Easy access to care: The patient and family have access to advice and to all aspects of palliative care (physical, psychological, social and spiritual) at their doorstep.
 - 2. More effective caring: Advice, training and additional support for the family is available so that they can become more effective in their role as care givers and feel abler to manage and cope.
 - 3. Access to complementary services: The home care team can facilitate liaison with complementary and supportive services when required. The patient and family do not have to go out seeking such support on their own.
 - 4. Maintains confidentiality: This is especially important for people with Cancer & HIV/AIDS who may otherwise be shunned by the community out of ignorance and due to misconceptions about the disease.
 - 5. Spreading awareness in the community: Wherever appropriate, home care programmes can be used to spread awareness about palliative care. It is often the case that when a family is nursing someone with cancer their friends and associates become more aware and are more willing to discuss issues around terminal care. The family being cared for, too, can become ambassadors for the cause.

- 6. Mobilizing local resources: Local support groups and volunteers can be mobilized to support patients and care givers living in their particular area. They would be more willing to do this not only because they may know or have personal ties with the people affected but because it is much easier for neighbours to help each other than travel long distances to do so.
- Home care thus provide an avenue where palliative care can be practiced in all its domains [Physical, Social, Psychological, Spiritual] most effectively.
- > The aim is to address "Total Pain" of patients and their Care Givers and improve the quality of life of the patients and their relatives.

What is the composition of a Home Care Team?

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

How Does a Home Care Function?

- Each team caters for an area served by the Sub Health Centre Health and Wellness Centre or Primary Health Centre - Health and Wellness Centre.
- ASHA will identify bed-ridden patients and others needing palliative care be offered home care visit. This is followed by visits by MPW/CHO for further assessment using Palliative care screening tool
- The first visit to the patient's home takes 2 Hours. The Palliative Care issues of the patient and the family are identified (Medical, Nursing and counseling). Urgent issues are addressed during the first visit.
- The patients are categorized into High, Middle and low priorities depending on their Palliative Care needs. The High priority patients are visited once/twice or more often every week. Middle priority patients are visited once a fortnight. Low priority patients are visited once a month. These priorities are changed as and when required.

What are the scope of services in home care?

The services that can be provided as part of home care vary from setting to setting. Following services are generally included as part of home care.



Figure 12: Services provided as part of home care

Documentation of the work

A case sheet for every registered patient is maintained by the team [Annexure 3]. Staff Nurse maintains a monthly Master Sheet which is daily maintained and verified by the CHO/MO. The ASHA worker will also maintain a log of the home visits arranged by her. [Annexure 1]

Universal precautions

Introduction

Faced with concerns about the spread of serious infections, hospitals and health centers have begun using a successful technique that is also appropriate in many other settings. Rather than waiting to find out who is contagious, they treat everyone as a potentially infected person. The name of this infection control method is "universal precautions"; and it gives a set of guidelines to follow when you come into contact with body fluids and wastes that carry germs. It is not a lot of extra work and it really pays off. Health Care Workers who might come into contact with blood and other body fluids to practice the following infection control practices at all times with everyone:

- > Hand washing
- > Use of Personal Protective Equipment [eg. latex gloves]
- > Cleaning and disinfecting of contaminated areas/instruments
- Proper disposal of waste materials

The concept of Universal Health Care Precautions emphasizes that all our patients should be treated as though they have potential blood/ body fluid borne infections and can infect the caring health care workers.

- 1. Hand washing
 - > Hand washing is the most important infection control measure to prevent illness
 - > The amount of illness can be drastically reduced, if hands are washed at proper times and with the proper techniques.
 - > Hands should be washed with soap for at least 30 seconds, rinse them thoroughly and dry thoroughly.
 - > Hand washing should occur immediately before and after any patient care activities



Figure 13: Steps of handwashing

- 2. Personal Protective Equipment [PPE]
 - Personal protective equipment, is "specialized clothing or equipment, worn by an employee for protection against infectious materials." The items include gowns, gloves, masks, respirators, cap, face shield and goggles. Suitable PPE should be used as per the guidance of Medical Officer or Nurse.
- 3. Cleaning and disinfecting of contaminated areas/instruments
 - Wear gloves and use disposable towels or other means of cleaning that will ensure against direct contact with blood, body fluids or feces.
 - Decontaminate the area with an approved germicide or 1:100 solution of household bleach 1% sodium hypochlorite.
 - > All used equipment must be thoroughly washed and disinfected.
- 4. Bio medical waste management
 - All the waste generated during home care should be handled as per the Bio Medical Waste Management Rules 2016.

Cat.	Type of Bag/ Container used	TYPE OF WASTE	Treatment Disposal options
Yellow	Non-chlorinated plastic bags Separate collection system leading to effluent treatment system	 a) Human Anatomical Waste b) Animal Anatomical Waste c) Soiled Waste d) Expired or Discarded Medicines e) Chemical Waste f) Micro, Bio-t and other clinical lab waste g) Chemical Liquid Waste 	Incineration or Plasma Pyrolysis or deep burial
Red	Non-chlorinated plastic bags or containers	Contaminated Waste (Recyclable) tubing, bottles, intravenous tubes and sets, catheters, urine bags, syringes (without needles) and gloves.	Auto/ Micro/Hydro and then sent for recycling. Not be sent to landfill
White	(Translucent) Puncture, Leak, tamper proof containers	Waste sharps including Metals	Auto or dry Heat Sterilization followed by shredding or mutilation or encapsulation
Blue	Cardboard boxes with blue colored marking	Glassware	Disinfection or auto/ Micro/ hydro and then sent for recycling.

Figure 14: Bio Medical Waste Category and colour codes

Home care Kit:

- For effective delivery of home based palliative care services the home care team will be provided a home care kit. The kit will be located in Sub Health Centre-Health and Wellness Centre
- ANM will be responsible for maintaining the home care kit. PHC will ensure an uninterrupted supply of contents of the kit. The contents of the kit will be procured from through existing state specific procedures. The funds for the same will be provided as part of NPCDCS budget. The suggested composition of home care kit is provided in Annexure 4.

- > The following steps are suggested while visiting people at home:
 - Know the patient and family well. Even if you know them, cross check before hand 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 your self 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 un comfortable 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 care giver
 - 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. **[Annexure 4]**
 - Plan further follow-up if required and date for next visit. Communicate this to the patient and family

Chapter 6 : Psychosocial and Spiritual Support in Palliative Care

Competency: Demonstrates an understanding and application of the principles of good communication in palliative care

Specific Learning Objectives

- List Do's and Don'ts when dealing with psychologically disturbed patient/family
- Describe the protocol for handling an emotionally disturbed individual
- Demonstrate the principles for handling difficult questions

Activity 3:

During the visit by the home care team, it was observed that Ms. Savitri was very anxious and distressed. She was crying repeatedly. She asked the Nurse, why did she develop this condition? She also expressed worries about her family

Discuss in small group

- How would you plan a communication session with Ms. Savitri?
- How would you like to include Savitri's children in the entire discussion?

Share in the large group

As a ASHA, 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 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.

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.

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 moneyto 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.

What are the needs of the patient?

- 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

What are the needs of the family?

- 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

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 are sponse.
- 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

• Main care give must do a psychosocial assessment of the patient. 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.

The nature of the patient'smood:

"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.

After the assessment, one must deal with these issues as best one can or, depending on their severity, identify them and inform to ANM.

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 worthless ness)
- Confusion (feel rejected and lost)
- Anger
- Denial
- Think no one is interested inthem
- Suspicion/Lack of trust
- Physical disability (for example have lost voice-box)
- Very often after the death of a patient care givers 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 care giver 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 care givers. We may ask: "What is your hope for your loved one?" Usually what patients and care givers 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 care givers 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. Care givers 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 care givers.
- 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 ASHA, 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 apriest.

Chapter 7: End of life care

Competency: Demonstrates awareness of the common issues associated with death and dying, and understands various ways of responding to them

Specific Learning Objectives

- Enumerate the signs of terminal stage/dying
- Enumerate common complaints [death rattle, agitation & Breathlessness]
- Describe a good death
- Describe the stages of bereavement
- Differentiate between normal & pathological grief
- Describe the process of death registration and obtaining death certificate

Activity 4:

Have you ever thought about your own death?

What kind of death would you like to have?

What kind of death would you consider as a Good Death?

Think about these questions independently

Volunteer to share with the group if you feel comfortable.

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 bed bound
- 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 the time of death
- * Document the discussion along with the names of the persons discussed with
- * Discuss the case with the MPW(F/M) concerned and document it
- Make the patient as comfortable aspossible.
- Give 'individualised care'
 - * Assess level of consciousness
 - * Find out the patient'swishes
 - * 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 mouthcare
- 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 canoccur
 - * Fluid can collect in the lungs

Review

- * All medicines taken by patient with doctor and find out if any 'non-important' medicines can best opted
- * Regular review is needed

Good symptom control:

- * Provide 'non-drug ' methods of symptom control
- * The patient is likely to pass urine and stool in bed. The caregivers should be taught how to clean the patient

Breathlessness

- * Consider non-pharmacological methods
 - Switching on fan
 - Staying with the patient and boosting morale
 - Gently stroking the back

Anxiety, restlessness and confusion

- * Look for causes like pain
- * 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'

Fits

- * Prevent the patient from self-harm. Do not force any object like a spoon into the mouth
- * 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

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 ofpatient
 - 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 heart beat, if a stethoscope if 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 MPW/Community Health Officer/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

Competency: Describe the importance of community participation in delivering effective palliative care

Demonstrates an awareness of the social support system and organizations working for social issues in the communities

Specific Learning Objectives

- Describe role of community in health care
- Describe the concept of community participation
- Describe the role of volunteers in the care of the incurably and terminally ill
- Describe one model of community participation in palliative care in India
- List potential organizations and other resource that can contribute to palliative care delivery system in local setting

Activity 5:

Pool the details of government and non-government agencies in the area from which a patient/family can get medical/ social/financial support

Discuss in small group and share with the large group

Develop this into a sharable resource list for the area

Adapted from: Palliative Care- A workbook for the carers, Institute of Palliative Medicine, Calicut.

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
- 5. It helps change social and cultural factors
- 6. It ensures that health services are accountable and provide good quality car

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

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.

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.

Chapter 9 : Palliative Care in National Health Programmes

Competency: Demonstrates an understanding of the palliative care service available through various national health programmes

Specific Learning Objectives

- Describe the Palliative Care as envisaged in National Health Policy
- Describe the salient features of National Programme for Palliative Care
- Describe the scope of palliative care under other national health programmes
- Describe the referral mechanisms for patients needing Palliative Care

Though our country has great need, palliative care has not been focus area for our health systems. However, over last decade there have been some patchy attempts to provide palliative care its due place in the public health system. These have been summarized below.

National Programme for Palliative Care [NPPC]:

National Programme for Palliative Care was launched in 2012. The programme is part of flexi pool under National Health Mission. Currently it has been integrated with National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS).

➢ Goal:

Availability and accessibility of rational, quality pain relief and palliative care to the needy, as an integral part of Health Care at all levels, in alignment with the community requirements.

> Objectives:

The key objectives of the programme are as following:

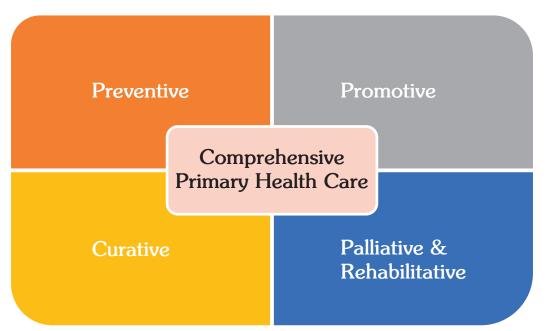
- Improve the capacity to provide palliative care service delivery within government health programs.
- Refine the legal and regulatory systems, support implementation to ensure access and availability of Opioids.
- Encourage attitudinal shifts amongst healthcare professionals
- Promote behaviour change in the community
- Develop national standards for palliative care

The major strategies proposed are provision of funds for establishing state palliative care cell and palliative care services at the district hospital.

National Health Policy:

The latest National Health Policy was adopted in the year 2017. The policy recognizes the growing need for palliative and rehabilitative care for all geriatric illnesses and advocates the continuity of care across all levels.

The objective of the policy is to "Improve health status through concerted policy action in all sectors and expand preventive, promotive, curative, palliative and rehabilitative services provided through the public health sector with focus on quality".



The policy denotes important change from very selective to comprehensive primary health care package which includes geriatric health care, palliative care and rehabilitative care services. It envisages enhanced capacity building related to Palliative care both in health services and training. Palliative care has also been considered to be part of Right to Healthcare by the policy.

Palliative Care in other National Programmes:

Recently Palliative Care services are also included under other national health programmes.

- National AIDS Control Programme has identified the palliative care as an important component of the car, support and treatment in managing the HIV pandemic. The focus is on symptom management of patients, psychosocial, spiritual and bereavement support for both patients and families. Home care has been considered to be of great importance in meeting the palliative care needs of HIV positive patients and families. Children (both HIV positive and negative have been identified as special focus group) Peer counsellors, outreach workers (ORW), link worker or ASHA are expected to play important role.
- National Tuberculosis Elemination Programme has also identified the unmet palliative care needs of palliative care especially in those suffering from drug resistant tuberculosis. Palliative care would be offered through the nodal DR-TB centers or at the community level under guidance of nodal DR-TB center. Necessary services include pain relief, psychosocial support, respiratory physiotherapy, nutritional support etc.

> Ayushman Bharat Yojana:

Ayushman Bharat Yojana launched in 2018, has two components:

- 1. Pradahan Mantri, Jan ArogyaYojana[Health Insurance Scheme]
- 2. Comprehensive Primary Healthcare through Health & Wellness Centres [HWC].

Palliative Care has been included as an expanded range of services along with Healthcare of the elderly. Support to the families in Palliative care and availability of basic pain management and palliative care services through HWC.

Chapter 10 : Roles and Responsibilities of ASHA in Palliative Care

Competency: Demonstrates an understanding of the roles, responsibilities, scope and ASHA in context of providing Palliative care to the communities

Specific Learning Objectives

- Describe the proposed role of Health & Wellness Centres in Palliative Care
- Describe the expected role of ASHA in Palliative Care
- The people in the community who suffer from chronic, incurably illnesses or are bed ridden face problems in day to day living as well as healthcare.
- 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 Frontline Workers comprising of MPW(F/M) and ASHA is the most important person linking up the patient, community and health institutions.

Roles and Responsiblities of ASHA in Palliative Care

• ASHA will identify bed ridden patients and others needing Palliative care.

While filling the Community Based Assessment Checklist, you will fill a question in the general information section-

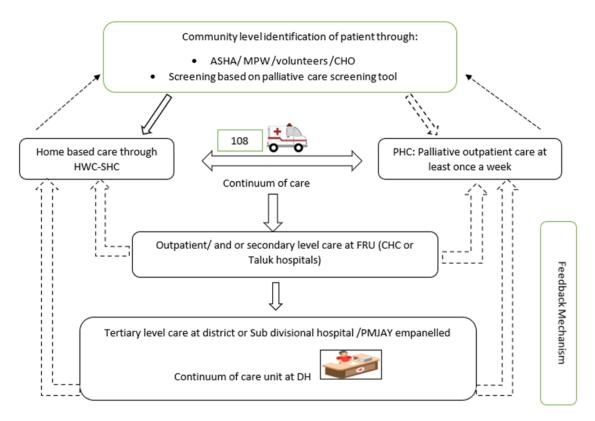
"Does this person have any of the following:

Visible defect/known disability/Bed ridden/require support for Activities of Daily Living"

If the answer to any of these is Yes, you will refer to the CHO for further assessment.

- Undertake regular home visits to the patients and provide psychosocial support to the patients and family members.
- ASHA will assist the family members in routine home care, simple nursing skills and accessing various service as needed including mobilization of local resources.
- Create awareness about palliative care.
- Identify and refer patients to the Community Health Officer as and when required.
- Identify community volunteers for palliative care.
- ♦ Work with MPW(F/M) to provide basic patient management services.
- Provide psychosocial support to the families/patients
- Facilitate affected families to get appropriate documentation to avail eligible social entitlements by linking them to Gram Panchayat or other relevant agencies.
- Escort the patient/family during initial visits to ensure better liaison between beneficiary and service providers.

- Render psychosocial support to the bereaved family as required.
- ASHA should be able to communicate compassionately with the patient and family, answering all their queries with knowledge, patience and understanding. She should also be able to communicate effectively with team members.
- Equip the care givers in performing simple nursing taskand should help them take suitable decisions and help them carry these out.
- ASHA will utilize meetings of the Village Health Nutrition and Sanitation Committee/Mahila Arogya Samiti (VHSNC/MAS) to raise awareness about the needs of palliative care patients, and mobilize individual and community level support, including accessing assistance available through other Government programmes.
- ASHA will identify a group of volunteers in her service area. Volunteers could be drawn from Youth Groups, Mahila Mandals, Co-operatives, Non-Governmental Organizations, etc.
- Follow the basic principles of caring such as safety of the patient and care giver, effectiveness of the interventions, provide physical and psychological support, appropriate use of resource, adequate knowledge and skill, providing individualized care.
- 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.
- ASHA will document the Palliative care services provided as per annexure 1 document and will submit the same at the Sub Centre as part of her monthly report
- ♦ ASHA identifies and refers those needing more care to ANM/ Community Health Officer. The referral pathway are as follows



Referral Pathway for patients in need of Palliative care

	Service Delivery framework of Palliative Care							
Care at Community Level	Care at SHC-HWC	Care at PHC-HWC	Care at secondary/ tertiary care facility					
 Awareness generation and community mobilization (MPW, CHO and ASHAs) Create awareness about palliative care, first level screening of patient/families for potential palliative care needs Home visits to the patients and provide psycho-social support to the families/patient (ASHA, Community volunteers) Linkage with community platforms, specific groups to raise awareness about 	 Community Health Officer Support Home Based care Provision of "Palliative care kit" and ensuring home based care for patients seeking exclusive AYUSH treatment. A list of hospices and trained palliative care physicians in the neighbourhood with their contact details will be maintained and shared with the community Provision of services 	 Medical Officer (MBBS) Provision of providing Palliative care Out Patient services at least once a week Prescribing appropriate drugs, including Oral Morphine and maintaining separate case sheet and patient card for palliative care patients Provision of home care and end of life care palliative care services for those who need it, on a 	 CHC-MOIC Provision of a dedicated palliative care Out Patient services at least once in a week for walk-in patients and those referred from PHCs/UPHCs. At least 5 beds to be earmarked for palliative care patients as apart of providing inpatient services. Ensuring continuum of care at the hospital, at higher level centre like District hospital and at home too as per the 					
 the needs of palliative care patients and mobilize individual and community level support Screening and Identification Identification of bed ridden patients and others needing palliative care and refer to CHO. Screening and Early Detection of the identified individuals using Palliative Care screening tool Identification of community volunteers. 	 of Yoga trainer and ICTC counsellor at the PHC-HWC to enable supportive supervision of the palliative care team at the Sub Centre – HWC . Providing "out of hours" care to those experiencing the final days of their life (End- of-life-care) and the death is duly reported to the HWC – PHC/ UPHC. Provision of bereavement support after the death of the patient. 	routine or emergency basis as required. • Necessary sensitization session should be carried out under the leadership of MO for caregivers, general public, representatives from PRI/Urban Local Bodies (ULB), students etc as these platforms are to generate volunteers and impart basic patient management and communication skills to volunteers, caregivers etc.	 need of the patient. Facilitating referral to district hospitals when needed Monitoring and supervision of activities of PHCs/UPHCs District Hospital/Sub Divisional Hospital level Provisions of OPD consultations geared at formulating a treatment / intervention plan and receive a prescription accordingly. 					

 Support family in identifying behavioral changes and providing care in elderly. Identifying group of volunteers to be trained in simple nursing skills. Monthly report submission based on the format of palliative care services 	 Ensuring social support by availing benefits from government and non-governmental programs/schemes to the eligible patients/ caregivers and to be displayed at the HWC. Creating Patient Support Groups and Care givers Support Groups with community volunteers and ensuring to convene the meeting once in a month presided by the CHO. 	 Ensuring referral services for secondary level of palliative care 	 Involvement of a trained medical social worker/ counsellor/ psychologist to ensure counselling/ psychosocial interventions/ psychoeducation The ICTC counsellor at the PHC shall be trained and deputed to extend this support wherever available. Ensuring inpatient treatment services including psychosocial and spiritual interventions, recreation facilities and formulating the plans for home based palliative care by involving patients and care givers Provision of Follow up from the OPD.

Annexure 1: Suggested format for documentation of Palliative Care Services

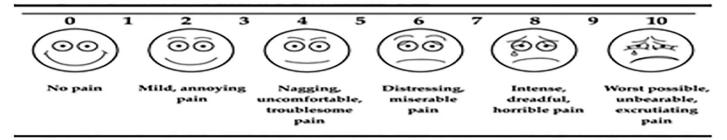
	Patients with	palliative ca	are needs			
Sr.No.	Name	Age/Sex	Diagnosis	Functional Diagnosis*	Screening score	Referral Yes/ No
1						
2						
3						
4						
5						
	Home care vi	sits		1	1	1
Sr. No.	Name	Age/Sex	Diagnosis	Functional Diagnosis*	Accompanied by	Main interventions
1						
2						
3						
	Sensitization	/ IEC activit	ies		1	
Sr. No.	No. of beneficiaries	Venue	Resource person		Type of beneficiaries	Method used
1						
2						
3						
* With re	espect to Activitie	s of Daily Livi	ng (ADL) - Indepe	ndent/Minimal s	support required/B	ed ridden

Annexure 2: Home Visit Case Sheet

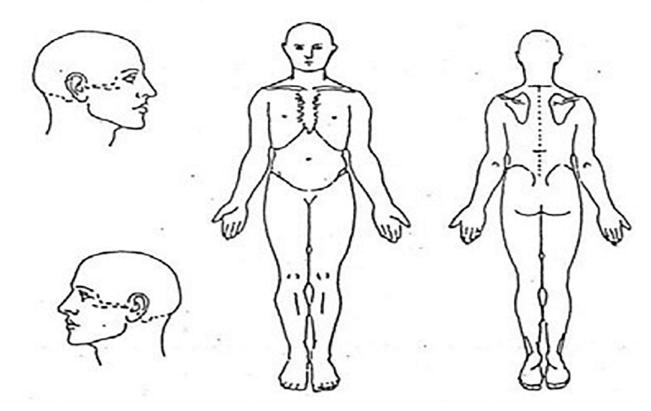
1. Name:		Age:y	rs Sex:	Religion:
2. Date of first contact wi	th family:			
3.				
Address: Other contact name & Address:		Telephone		Useful info/remarks-route with distance, landmarks etc.
4. Informant, if other than	patient:	R	lelation to the p	patient:
5. Family tree: Other relevant family relate	d info			
6. Social background:				
Occupation : Current				
No. of members in the fam			ng tamily memb	oers:
	vith chronic disease (details):	1		
Primary care giver: Other support :				
	scheme cards : BPL / APL /	Ayushman E	3harat/ State S	pecific cards
7.Diagnosis: [Include all the	e diseases/ disabilities]			
8. Treatment Status:				. 1
Ongoing treatment:		Previous trea	atment/s for th	is condition:
ECOG performance status:				
0-Normal activity	1-Ambulatory + Light work		2- Ambulator	y Self Care [No work]
3-Limited Self care / Confi	ned to bed or chair mostly	4-Completel	y disabled, No	self care
General condition	Fairly good / Poor / Debilit state	tated / Very v	veak / Drowsy	/ Unconscious/ Terminal
Communication	Easy / Occasionally / With	drawn /Non-	communicative	2
Main concerns				
Sleep	Normal /Disturbed /Wakef	ul nights (reas	son)	
Urination	Normal / Hesitancy/ Increa	ased frequenc	y / Incontinen	ce / on catheter
Bowel	Normal /Diarrhoea / Cons	tipation /Stor	ma	
Malodour	Due to incontinence/ Infec	ted ulcer		
Appetite	Good / Fair / Poor / None	2		

	symptoms: (by pat	ient / i	nforma	nt)			
Pain			Sore n	nouth		Itching	
Nausea			Swellir	ng		Agitation/irrelevant talk	
Vomiting	g		Ulcer/	Wound		Tiredness	
Swallow	ving difficulty		Bleedin	ng		Drowsiness	
Heart bi	urn		Lymph	ioedema		Others (List below)	
Constipa	ation		Pressu	re sores			
Loose n	notions		Urinar	y problems			
Cough							
Breathle	essness						
	stressing symptom						
Social a	nd emotional issue	s:					
Psycholo	ogical assessment:						
Toyonok							
			Patier	nt		Family	
Insight a	about Disease		Patier Compl	nt ete / Partial /	No	Family Complete / Partial / No	
	about Disease about prognosis		Compl				
Insight a		ns	Compl Compl	ete / Partial /	No	Complete / Partial / No	
Insight a Acceota	about prognosis	ns	Compl Compl	ete / Partial / ete / Partial /	No	Complete / Partial / No Complete / Partial / No	
Insight a Acceota Pain Ass	about prognosis nce of the conditio	ns	Compl Compl	ete / Partial / ete / Partial /	No	Complete / Partial / No Complete / Partial / No	
Insight a Acceota Pain Ass D Patie	about prognosis nce of the conditio sessment: ent has no pain.		Compl Compl Compl	ete / Partial / ete / Partial / ete / Partial /	No No	Complete / Partial / No Complete / Partial / No	
Insight a Acceota Pain Ass D Patie	about prognosis nce of the conditio sessment: ent has no pain.		Compl Compl Compl	ete / Partial / ete / Partial / ete / Partial /	No No Poor / not on Character (A	Complete / Partial / No Complete / Partial / No Complete / Partial / No	Provoking/ Palliating factor
Insight a Acceota Pain Ass Patie Effective	about prognosis nce of the conditio sessment: ent has no pain. eness of present pa	in mec	Compl Compl Compl	ete / Partial / ete / Partial / ete / Partial / Good / Fair /F Type (Constant/	No No Poor / not on Character (A	Complete / Partial / No Complete / Partial / No Complete / Partial / No any pain medication Aching/ Throbbing /	Palliating
Insight a Acceota Pain Ass Pain Effective Site	about prognosis nce of the conditio sessment: ent has no pain. eness of present pa	in mec	Compl Compl Compl	ete / Partial / ete / Partial / ete / Partial / Good / Fair /F Type (Constant/	No No Poor / not on Character (A	Complete / Partial / No Complete / Partial / No Complete / Partial / No any pain medication Aching/ Throbbing /	Palliating

(A) Mark the pain intensity



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



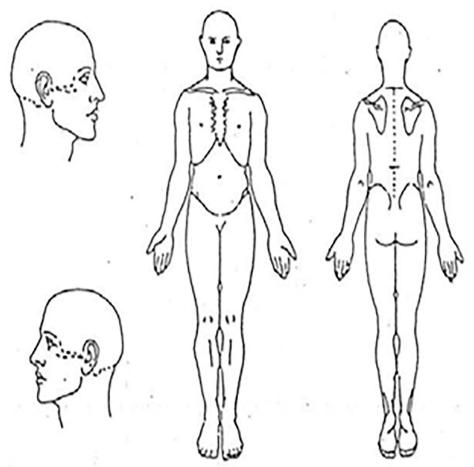
Brief Management Plan:

Annexure 3: Follow up Case Sheet

Name of the patie		Age:	_ Sex:	_ Date:					
Type of visit: Rou	Type of visit: Routine /Emergency								
ECOG performance status: 0 / 1 / 2 / 3 / 4									
General condition	Fairly good / Poo Terminal state	r / Debilitated / Cache	ctic / Very w	eak / Drowsy	/ Unconscious/				
Feeling	Good /Comfortal Patient says:	Good /Comfortable / Bad /Amgry/ Sad / Anxious/ Depressed Patient says:							
Communication	Easy / Occasional	lly / Withdrawn /Non-	communicati	ve					
Ambulation/ Activity	Normal activities , bound	/ Limited activities (nee	eds support) ,	/ Needs assist	ance for ADL/ Bed				
Main concerns									
Sleep	Normal /Disturbe	d /Wakeful nights (reas	on)						
Urination	Normal / Hesitan	cy/ Increased frequenc	y / Incontine	nce / on cath	neter				
Bowel	Normal /Diarrhea	a / Constipation /Stom	a						
Maldour	Due to incontinen	nce/ Infected ulcer							
Appetite	Good / Fair / Poo	or / None							
Present symptoms	s: (by patient / info	ormant)							
Pain		Sore mouth		Itching					
Nausea		Swelling		Delirium					
Vomiting		Ulcer		Breathless	ness				
Swallowing difficu	ılty	Bleeding		Tiredness					
Heart burn		Lymphoedema		Drowsines	5				
Cough		Pressure sores		Others (Lis	t)				
Most distressing	symptoms:	·							
Distress level:									

Social and emotional issues:								
Spiritual issues:								
Pain Assessment:								
Patient has no	o pain.		Family's input sa	ame / different				
Effectiveness of p	reset pain medicin	e: Good / Fair /Po	oor / not on any pa	ain medication				
Site	Intensity (0-10)	Duration	Type (Constant/ Intermittent)	Character	Provoking/ Palli- ating factor			
А								
В								
С								
D								

Systemic Examination:



Treatment advised (Pharmacological & Non-pharmacological):

Annexure 4 : Home Care Kit

Supplies	Medicines
Equipment	Pain Control
1. Stethoscope	1. Paracetamol
2. BP Apparatus	2. Ibuprofen
3. Torch	3. Diclofenac
4. Thermometer	4. Tramadol
5. Tongue Depressors	
6. Forceps	
Supplies	Wound Management
1. Dressing Supplies	1. Betadine Lotion and Ointment
2. Cotton	2. Metrogyl Jelly
3. Scissors	3. Hydrogen Peroxide
4. Gauze Pieces	
5. Gauze bandages	
6. Dressing Trays	
7. Gloves	
8. Micropore Tapes	
9. Syringes and Needles	
10. Condom Catheters	
11. Urine Bags	
12. Feeding Tubes	
Gastrointestinal Symptom Management	Antibiotics and Antifungals
1. Domperidone	1. Ciprofloxacin
2. Bisacodyl	2. Metronidazole
3. Loperamide	3. Amoxycillin
4. Oral Rehydration Salts	4. Fluconazole
5. Ranitidine	
Psychological Symptom Management	Nutritional Supplements
1. Lorazepam	1. Iron, Vitamin and Mineral Supplements
2. Amitriptyline	2. Other Miscellaneous
	3. Spirit
	4. Lignocaine Jelly
	5. Ethamsylate
	6. Deriphylline
	7. Cough Preparations

Annexure 5 : Community Based Assessment Checklist

Community based a			CBAC)	
revised dra	aft 6 October 20	20 V.5		D 0 0 1 4 4 4 4 4 4
			Date: D	D/MM/YYYY
General Information		1		
Name of ASHA:		Village/Ward:		
Name of MPW/ANM:		Sub Centre:		
		PHC/UPHC:		
Personal Details				
Name:	Any Identifier (etc.):	Aadhar Card/ a	any other UID	– Voter ID
Age:	State Health In If yes, specify:	surance Schem	es:Yes/No	
Sex:	Telephone No.	(self/family me	mber /other -	specify details):
Address:				
Does this person have any of the following: visible defect /known disability/Bed ridden/ require support for Activities of Daily Living	If yes, Please specify			
Part A: Risk Assessment				
Question	Range		Circle Any	Write Score
1. What is your age? (incomplete years)	0 – 29 years		0	
	30 – 39 years		1	
	40 – 49 years		2	
	50 – 59 years		3	
	60 years		4	
2. Do you smoke or consume smokeless prod-	Never		0	
ucts such as gutka or khaini?	Used to consume in the past/ Sometimes now		1	
	Daily			
3. Do you consume alcohol daily	No		0	
	Yes		1	
4. Measurement of waist (in cm)	Female	Male		
	80 cm or less	90 cm or less	0	
	81-90 cm	91-100 cm	1	
	More than 90	More than	2	
	cm	100 cm		

FD 1.11 1.1.1.	··· (A.1 . 150 · · · ·		[
5. Do you undertake any physical activities for minimum of 150 minutes in a week?		At least 150 minutes in a week	0	
(Daily minimum 30 minutes per day	i - Five	Less than 150 minutes in a	1	
days a week)	, 1100	week	-	
6. Do you have a family history (any or	ne of your	No	0	
parents or siblings) of high		Yes	2	
blood pressure, diabetes and heart disease?				
Total Score				
Every individual needs to be screened i	rrespective	e of their scores.		
A score above 4 indicates that the pers tending the weekly screening day	son may be	e at higher risk of NCDs and ne	eeds to be prior	itized for at-
Part B: Early Detection: Ask if P	atient ha	s any of these Symptoms		
B1: Women and Men	Y/N			Y/N
Shortness of breath (difficulty in breathing)		History of fits		
Coughing more than 2 weeks*		Difficulty in opening mouth		
Blood in sputum*		Any ulcers in mouth that has two weeks	not healed in	
Fever for > 2 weeks*		Any growth in mouth that has two weeks		
Loss of weight*		Any white or red patch in mo not healed in two weeks		
Night Sweats*		Pain while chewing		
Are you currently taking anti-TB drugs**		Any change in the tone of you	ur voice	
Anyone in family currently suffering from TB**		Any hypopigmented patch (es lesion(s) with loss of sensatior		
History of TB *		Any thickened skin		
Recurrent ulceration on palm or sole		Any nodules on skin		
Recurrent tingling on palm(s) or sole(s)		Recurrent numbness on palm	(s) or sole(s)	
Cloudy or blurred vision		Clawing of fingers in hands a		
Difficulty in reading		Tingling and numbness in har feet		
Pain in eyes lasting for more than a week		Inability to close eyelid		
Redness in eyes lasting for more than a week		Difficulty in holding objects w fingers		
Difficulty in hearing		Weakness in feet that causes walking	difficulty in	

Y/N				Y/N	
	Bleeding after :				
	Bleeding after	Bleeding after intercourse			
	Foul smelling v	aginal discharge	2		
Y/N				Y/N	
	Needing help from others to perform everyday activities such as eating, getting dressed, grooming, bathing, walking, or using the toilet				
	Forgetting names of your near ones or your own home address				
		Bleeding after Bleeding after Bleeding after Foul smelling v Y/N Needing help f everyday activit dressed, groon using the toilet Forgetting name	Bleeding after menopause Bleeding after intercourse Foul smelling vaginal discharge Y/N Needing help from others to p everyday activities such as eati dressed, grooming, bathing, w using the toilet Forgetting names of your near	Bleeding after menopause Bleeding after intercourse Foul smelling vaginal discharge Y/N Needing help from others to perform everyday activities such as eating, getting dressed, grooming, bathing, walking, or using the toilet Forgetting names of your near ones or your	

*If the response is Yes- action suggested: Sputum sample collection and transport to nearest TB testing center

** If the answer is yes, tracing of all family members to be done by ANM/MPW

Part C: Risk factors for COPD

Circle all that Apply

Type of Fuel used for cooking – Firewood / Crop Residue / Cow dung cake / Coal / Kerosene / LPG

Occupational exposure – Crop residue burning/burning of garbage – leaves/working in industries with smoke, gas and dust exposure such as brick kilns and glass factories etc.

Part D: PHQ 2								
Over the last 2 weeks, how often have you been bothered by the following problems?			Not at all	Several days	More than half the days	Nearly every day		
1.	1. Little interest or pleasure in doing things?		0	+1	+2	+3		
2.	Feeling down, depressed or hopeless?		0	+1	+2	+3		
Tota	Total Score							
Any	Anyone with total score greater than 3 should be referred to CHO/ MO (PHC/UPHC)							

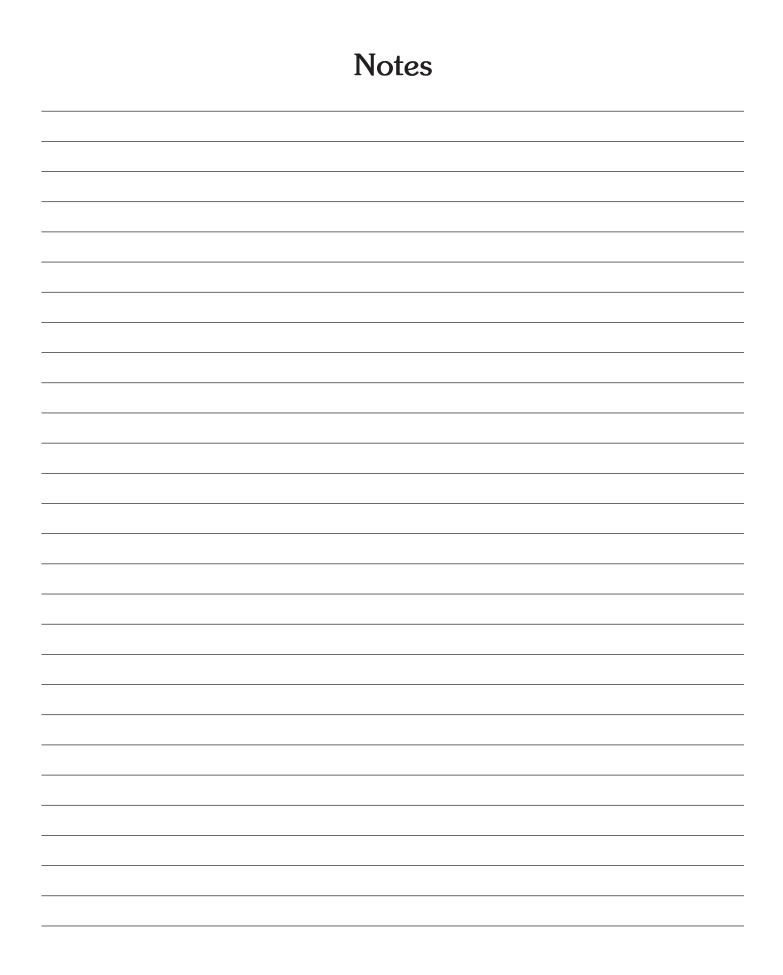
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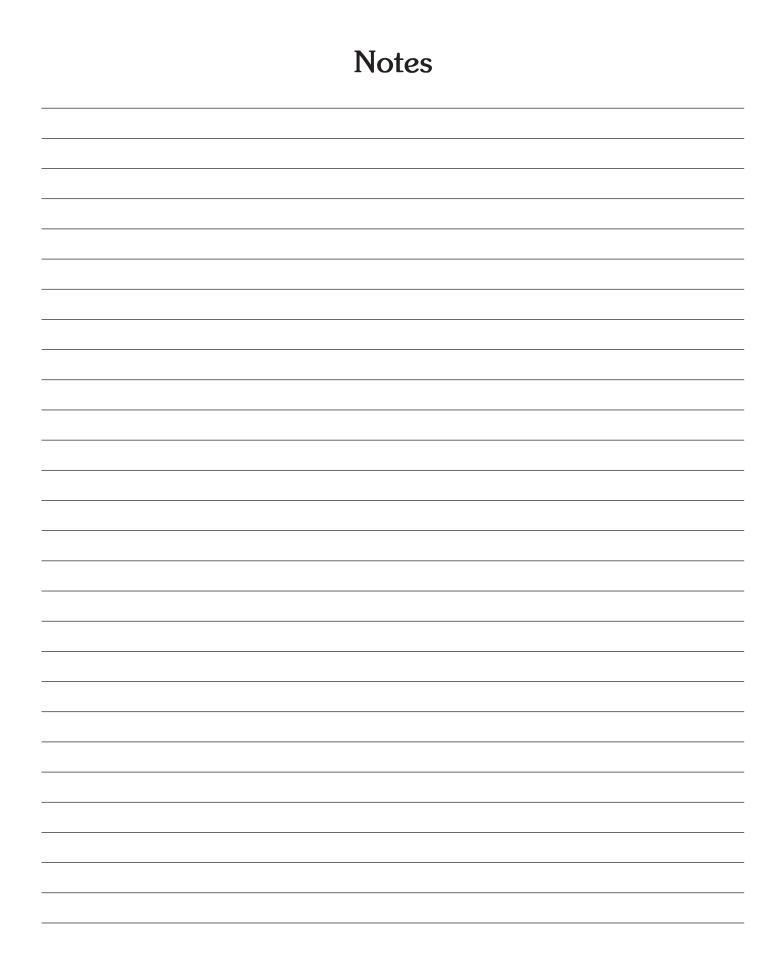
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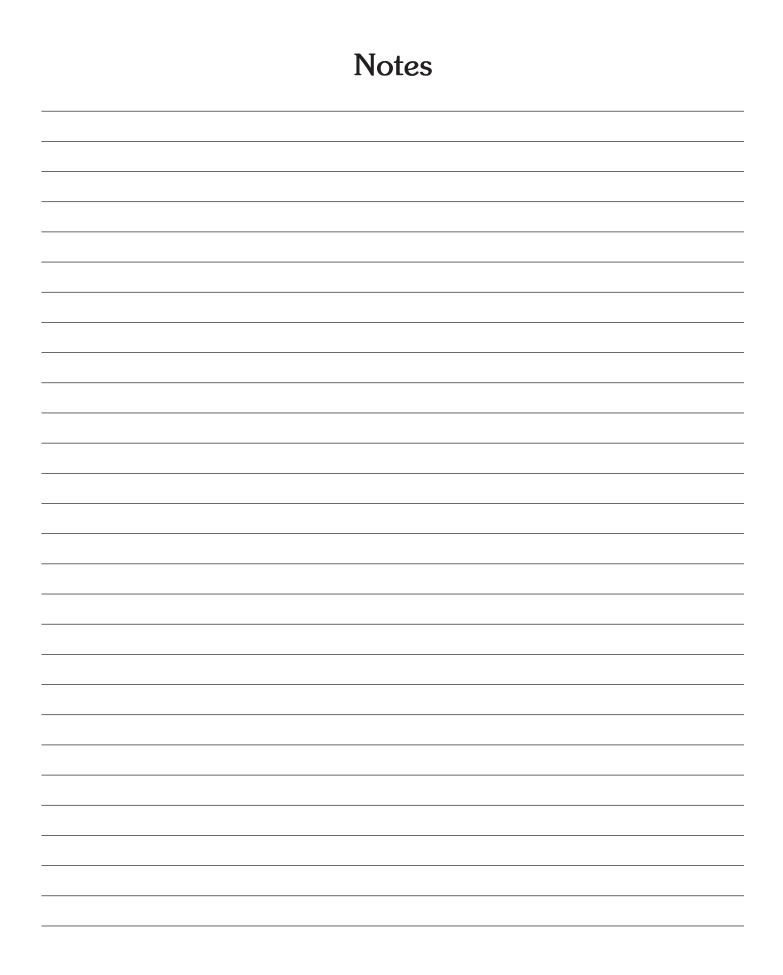
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Namaste!

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

To reach out to community members about the services at AB-HWCs, do connect to the following social media handles:

- 6 https://instagram.com/ayushmanabhwcs
- 5
- https://twitter.com/AyushmanHWCs
- 🚽 h
- https://www.facebook.com/AyushmanHWCs
- https://www.youtube.com/c/NHSRC_MoHFW



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