



A Guide to

Basics of

Palliative Care



Objective

This booklet educates about how palliative care is crucial for the medics, paramedics and common man, as it ensures that those facing life-limiting conditions can live their remaining days with dignity and comfort. It's not just for the terminally ill, but for anyone dealing with chronic or severe health issues. Understanding palliative care can lead to better decision-making, improved communication between patients and healthcare providers, and ultimately, a more compassionate and supportive healthcare system.

When you go through this booklet you will learn about-

1. Palliative care and it's needs
2. Principles of palliative care
3. When, where and how to access palliative care
4. Cancer pain- A guide to cure
5. Opioids- shifting paradigm in cancer pain management
6. End of life care
7. Community palliative care
8. Family- Axis keeping everything in place
9. The multidisciplinary team approach



QUESTION 1

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 life.

Palliative care:

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





Who Needs Palliative Care ?

- ◆ Cancer patients
- ◆ HIV/AIDS patients
- ◆ Chronic Heart diseases patients e. g Chronic Heart failure, heart transplant patients, patients with intracardiac devices
- ◆ Patients with Chronic lung diseases
- ◆ Patients with Chronic kidney diseases
- ◆ Patients with Chronic neurological diseases eg- Parkinson's diseases Stroke or spinal cord injuries
- ◆ Old age conditions like Alzheimer's disease, dementia etc.
- ◆ Children with chronic life limiting diseases, cerebral palsy or birth defects etc.



QUESTION 3

What Are The Principles of Palliative Care ?

- ◆ 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/her so it looks after the patient as well as the family.



QUESTION
4

What constitutes a Palliative Care Team ?

It constitutes various specialists working together i.e palliative care physicians, nurses, social workers, spiritual care guides, community health workers, physiotherapists as well as the care givers. Community based volunteers, health workers are very important members of this team.

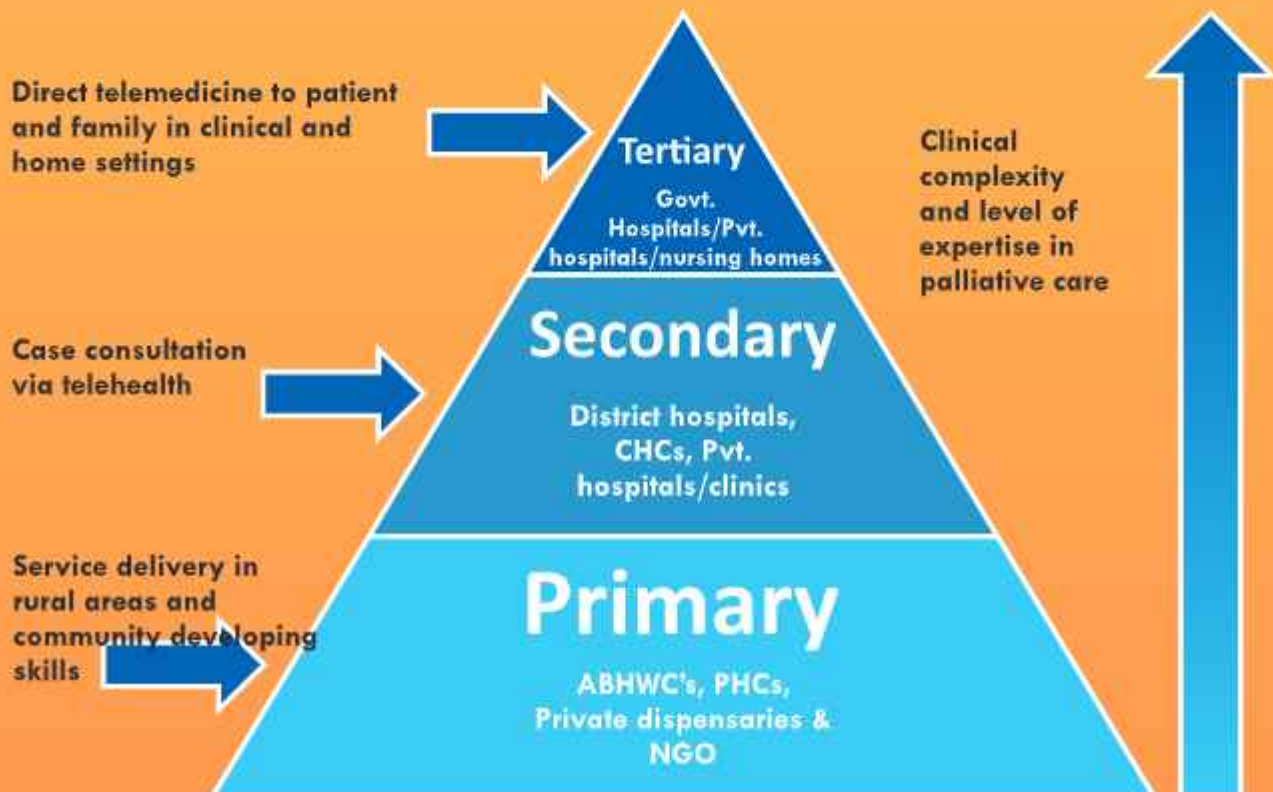




Where can we access Palliative Care Services ?

- ◆ Palliative care can be given anywhere - at home, in the hospital or in a place for the terminally sick which is called a 'hospice'.
- ◆ Traditionally home care is considered better by patients in India as they are more comfortable and familiar in their own home.
- ◆ Additionally it is cheaper & family care giving is feasible without having to undertake long travel or lose out employment.
- ◆ Provision of palliative care at different levels

LEVELS OF EXPERTISE IN PALLIATIVE CARE

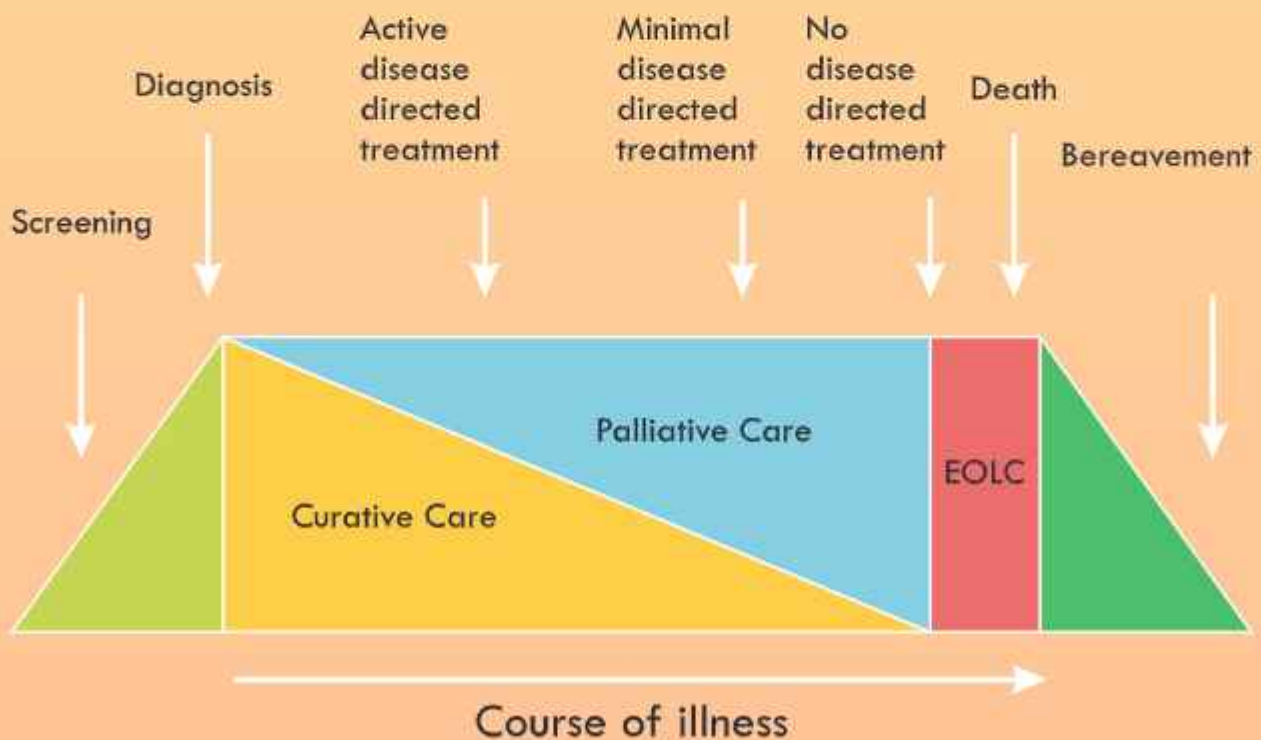


QUESTION
6

When should we initiate Palliative Care Services ?

- ♦ To yield best results, palliative care should be started as early as possible ,preferably from the time of diagnosis.
- ♦ It also helps build trust, plan ahead to prevent symptoms and have timely discussions with the family .
- ♦ It helps plan for good end of life care (EOLC) by making wise, well-informed and timely decisions when the disease is advanced.

Continuum of Palliative Care



QUESTION
7

How do you define pain? What is Cancer pain and how to manage it according to WHO stepladder ?

- ♦ Pain is an unpleasant sensory and emotional experience associated with or resembling that associated with, actual or potential damage as per revised IASP (International Association for Study of Pain)
- ♦ It is one of the most common symptoms in cancer patients. Pain can be caused by cancer, cancer treatment, or a combination of factors. Tumors, surgery, chemotherapy, radiation therapy, targeted therapy and diagnostic procedures may cause you pain.
- ♦ Three step ladder of managing cancer pain:



QUESTION 8

How can we use opioids safely in Palliative Care Practice ?

The safe use of opioid practice for pain and palliative care includes :

- ♦ Awareness and acknowledgement of pain
- ♦ Strict application of patient selection criteria to start opioid therapy
- ♦ Education and empowerment of physicians
- ♦ Ascertaining responsibility & easy availability of opioids
- ♦ Patient and family education
- ♦ Responsible dispensing, stringent supervision by family and physician
- ♦ Proper titration by physician
- ♦ Ultimately developing trust between the doctor and patient





What is End of Life Care (EOLC)?

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.

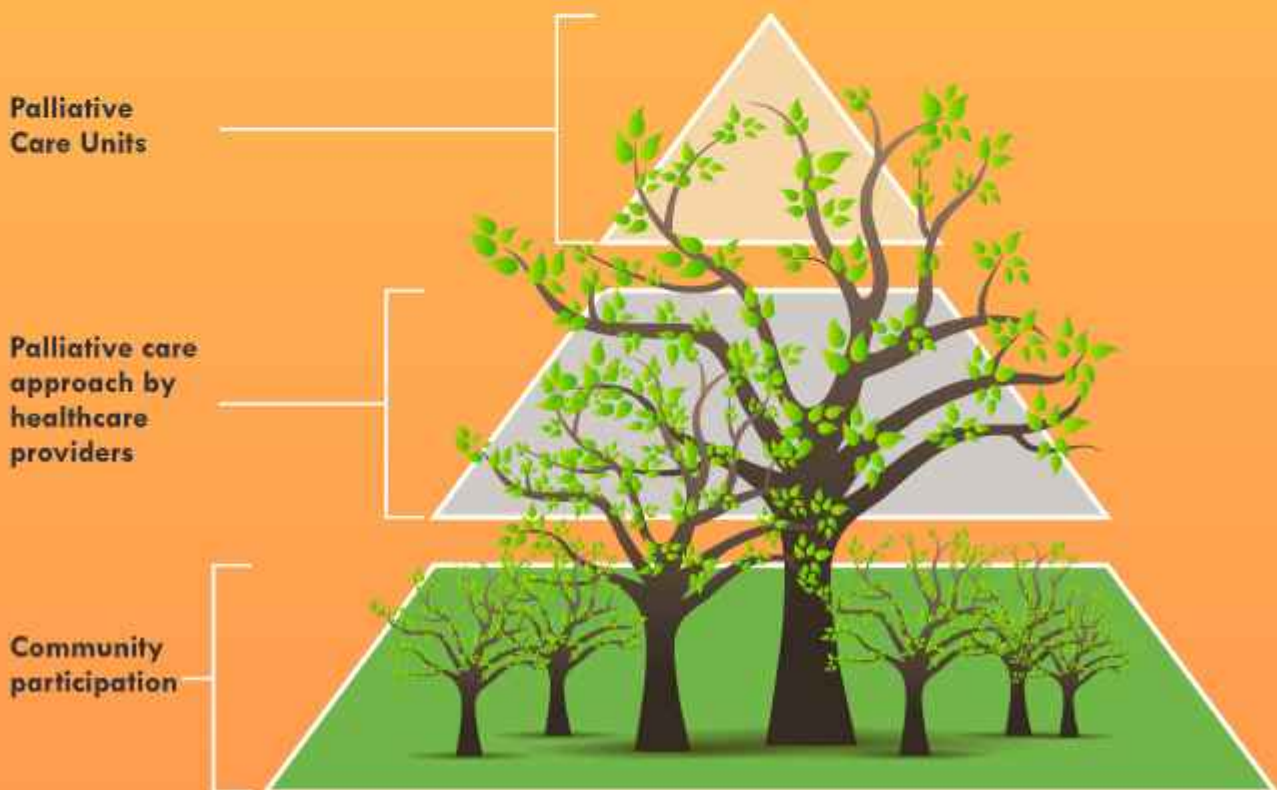


QUESTION
10

What constitutes community in Palliative Care ?

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. Community mobilization of resources (money, manpower, time etc)
2. Community involvement by taking responsibility for identifying patients and caring for them



QUESTION 11

What are the benefits of Community Participation ?

- ◆ The patients and families get health services nearby.
- ◆ The community benefits through improving skills, confidence and empowerment.
- ◆ Awareness and acceptability of palliative care.
- ◆ Positive outlook towards incurable diseases.
- ◆ It helps alter social and cultural acceptance.
- ◆ Sustained availability, acceptability and provision of good quality care.





Who can be a Community Volunteer ?

Anyone who wants to volunteer to help the patients
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.





What is the 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 providing information and training so that they can look after the patients with help from the volunteers.



QUESTION 14

What is the role of Physiotherapist in Palliative Care?

- ◆ Physiotherapists help manage pain through various techniques manual therapy.
- ◆ Exercise and positioning to enhance comfort and reduce discomfort.
- ◆ Work to maintain or improve a patient's mobility and functional abilities, which can enhance independence and overall well-being.
- ◆ Assist in managing respiratory symptoms, such as breathlessness and secretion clearance, which are common in palliative care patients.



QUESTION
15

What is the role of Social Worker in Palliative Care?

Social workers in palliative care helps:

- ◆ Address emotional, psychological, and social aspects of patients and their families.
- ◆ Facilitate communication between patients, families, and the healthcare team.
- ◆ Connect patients and families with community resources, financial assistance, and support services to address practical needs.



QUESTION 16

What is the role of spirituality in Palliative Care ?

It helps individuals find meaning and purpose, providing a source of strength and hope during challenging times. Spiritual care professionals, engage in active listening, prayer, and rituals tailored to patients' beliefs. It fosters a sense of connection, community, and comfort.



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**Comfort in every moment,
Dignity in every breath**

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