

# Community Participation in Palliative Care For FLW





# LEARNING OBJECTIVES

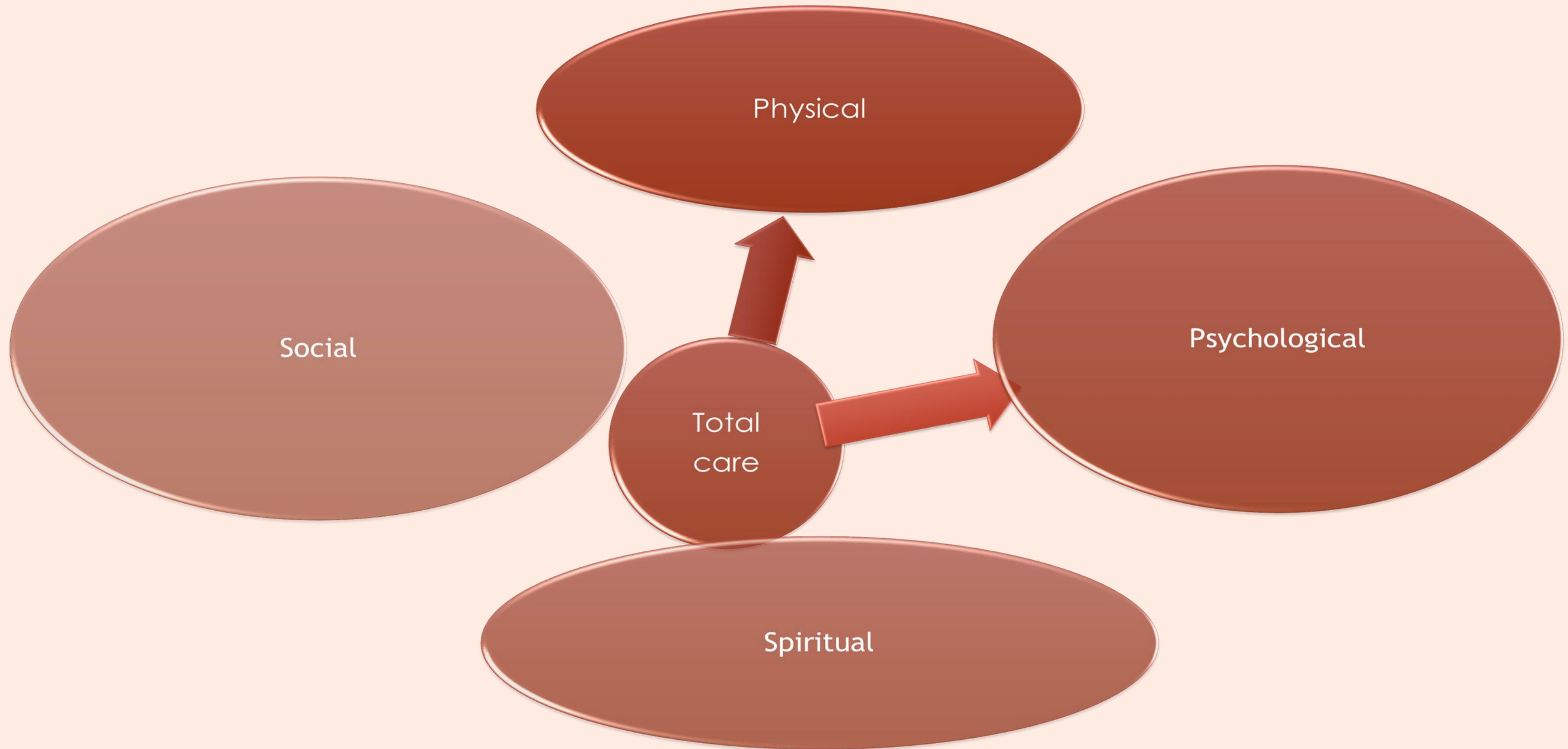
By the end of the session participants will be able to answer:



- What is Community Participation?
- Why is it is a must in Palliative Care
- Who are the Key Players in Palliative Care and what can they do?

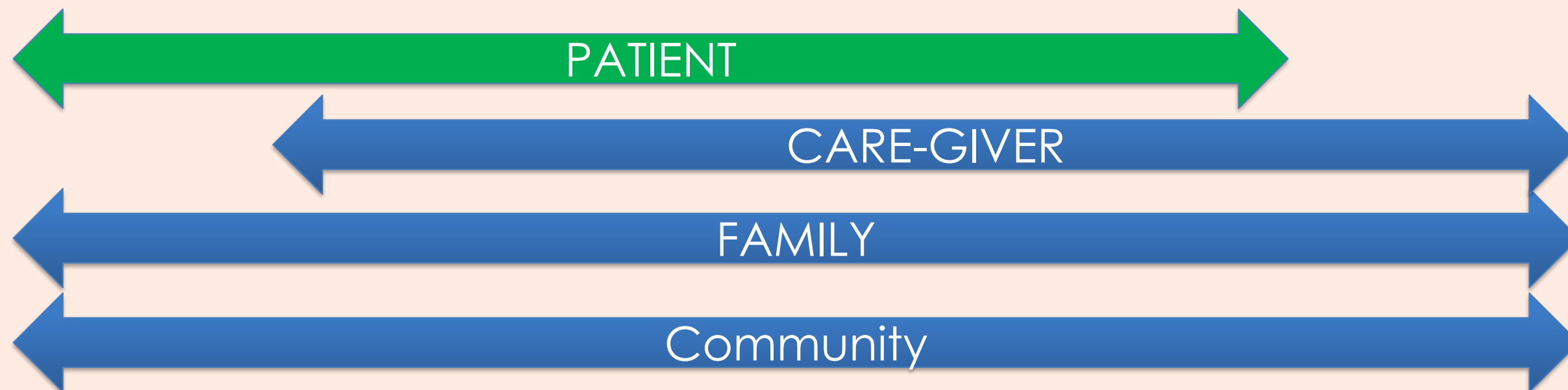
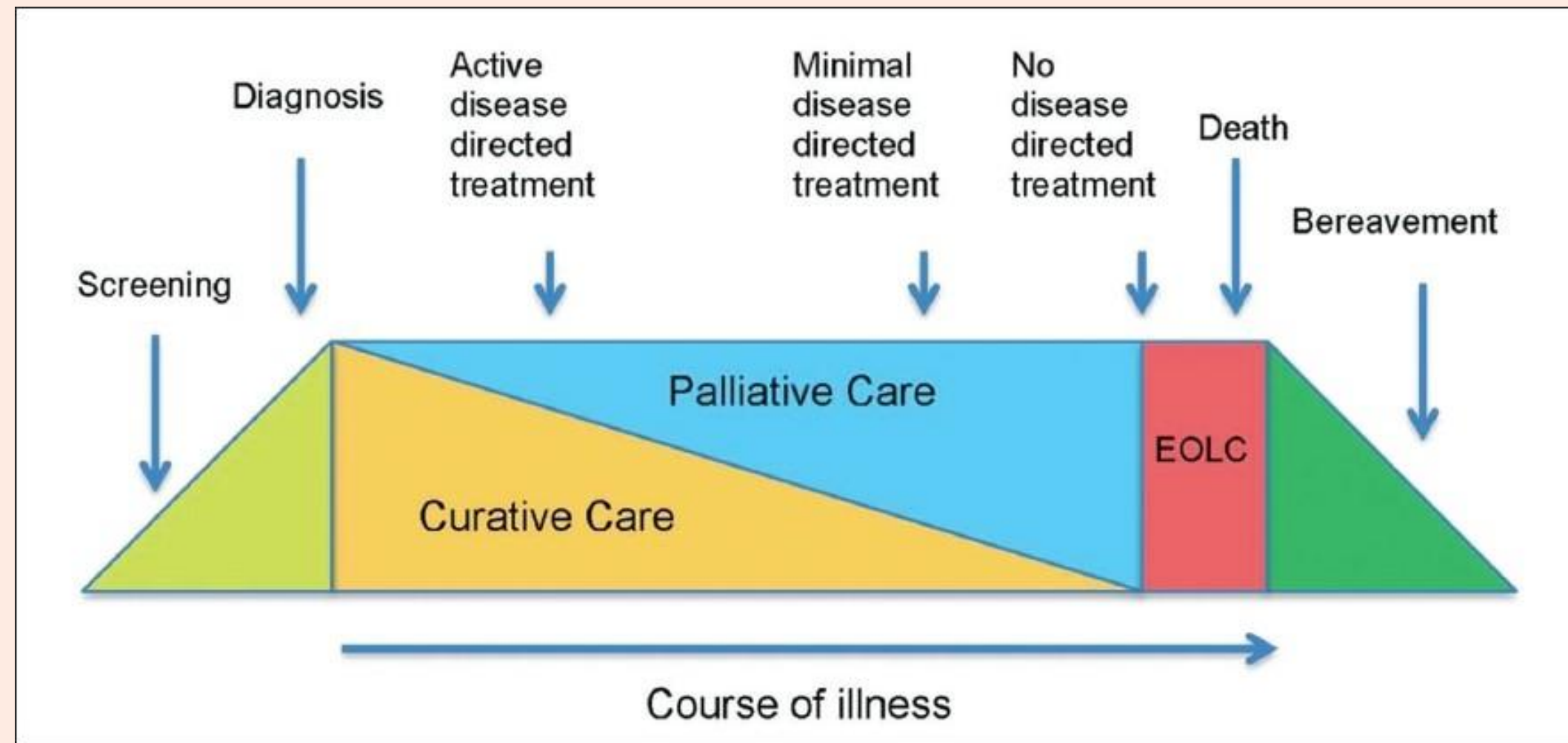


# TOTAL CARE



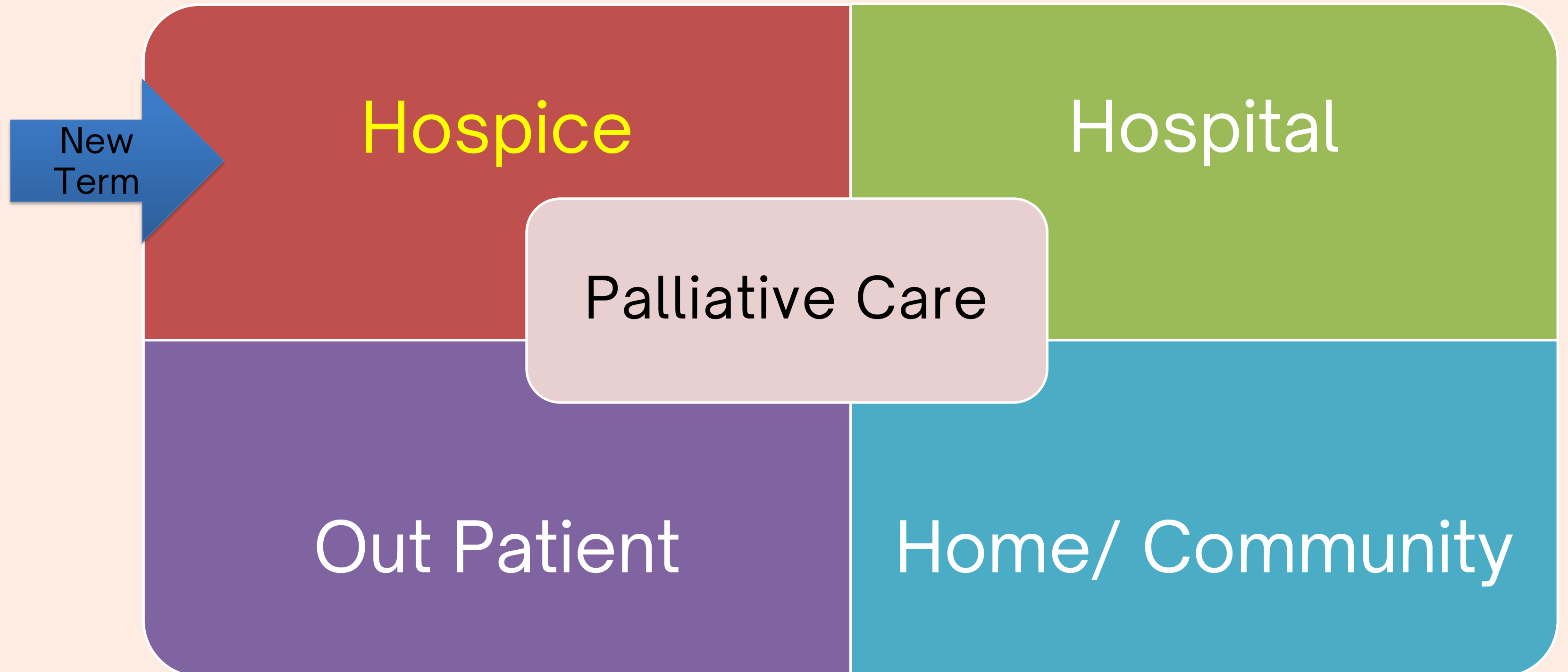


# CONTINUUM OF PALLIATIVE CARE AND COMMUNITY





# COMPONENTS OF PALLIATIVE CARE



# 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:
  - *Helping through resources (money, manpower, time etc.)*
  - *Taking responsibility for identifying patients and caring for them*
- Every member of Community cannot contribute equally





# COMMUNITY PARTICIPATION

- **Cost effective** method of providing elderly and palliative health services
- People begin to view elderly and palliative health more objectively, they are **more likely to accept the care**
- **Greater commitment** of the people resulting in the success of health care services
- **Promotion** Health awareness for community
- Health workers **get support** for their activities
- Health care services become **more relevant** to the health needs of the people
- **Quality** of health care improves

# 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 **change social and cultural factors**
- It ensures that **health services are accountable** and provide **good quality care**







# KEY PLAYERS



1. Community Volunteers
2. Families
3. Primary Health Care workers-  
ASHA/MPW



# COMMUNITY VOLUNTEERS

- Someone who works for the community
- They choose to do so
- Types:
  - **Untrained Volunteers:** someone who help in social support system (e.g. -----)
  - **Trained Volunteers:** someone who undergone formal training in palliative care and get involved in direct patient care (e.g. -----)





# COMMUNITY VOLUNTEERS-ROLES

- Emotional support
- Basic nursing care
- Linking up with the professional team
- Rehabilitation support
- Social support

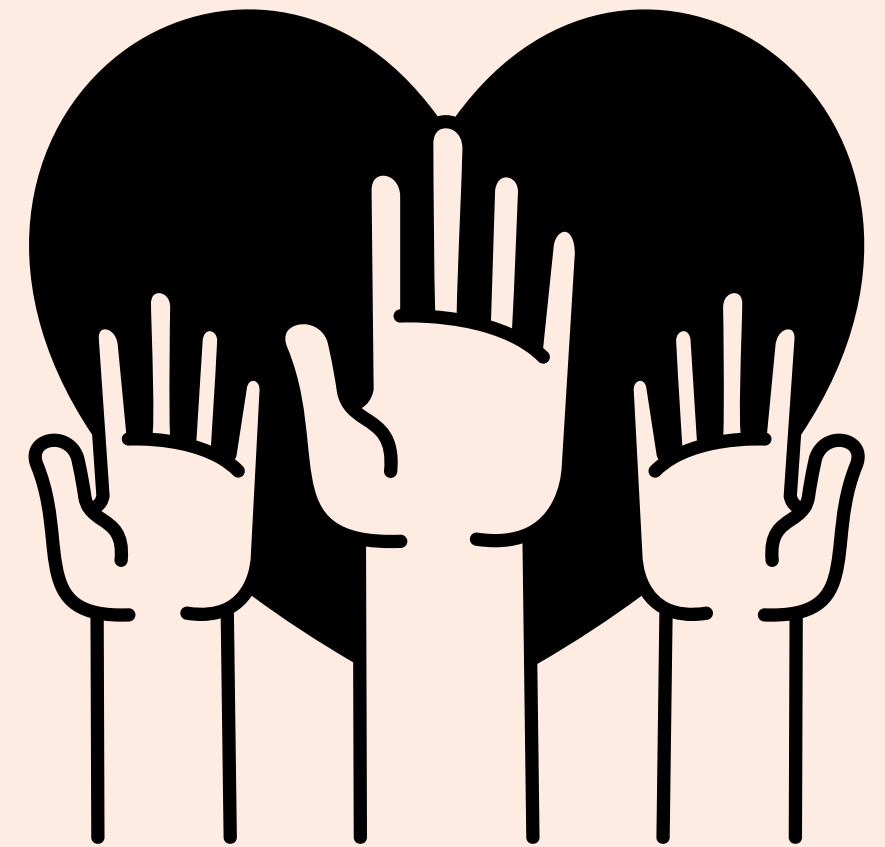




# COMMUNITY VOLUNTEERS-ROLES

**Social support** to the affected family by way of:

- Food for the family
- Educational support for children
- Helping with transport to hospital
- Linking with other support groups



# COMMUNITY VOLUNTEERS-ROLES

## Rehabilitation services.

- Regular awareness program in the community
- Training the family members to look after the patient
- Training volunteers in the community
- Administrative management of the unit
- Fund raising





# PRIMARY HEALTH CARE TEAM-ROLE

- Undertake 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.





# PRIMARY HEALTH CARE TEAM-ROLE

- Identify community volunteers for palliative care.
- 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.



# FAMILY MEMBERS-ROLE

- Most Important role as they are with the patient round the clock
- They come first into picture and can be affected even after the death of patient.
- Have to learn:
  - Home care skill
  - When to call for help (danger signs)
  - How to involve as a “unit”
  - How to handle their own emotional distress
  - Options/ scheme available for financial support





# HOW TO MOBILISE A COMMUNITY?



Mobilizing means encouraging and motivating the people

- First step = Creating awareness
- Repeated meetings with self-help groups, organisations of women and elderly citizens, village administration, schools, involvement in festival and religious gathering etc. are helpful.
- Ensure that minority groups, low status groups and poorer groups in the community are included





# PRIMARY HEALTH CARE TEAM-ROLE

- 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 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.



# CASE FOR GROUP ACTIVITY

Rahul, a 41 years old male ,married, middle class family, shop keeper near a temple. He has a foul smelling ulcer over left cheek. He lives with his wife, 13 years old son, 8 years old daughter. He is diagnosed as Stage IV Cancer of cheek and tongue, There is no further treatment from oncology. He is the only bread earner for family

## QUESTION

**Group 1: Role of Community volunteer**

**Group 2: Role of Family**

**Group 3: Role of ASHA/ MPW**





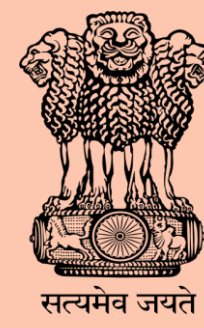
# EVALUATION

1. Untrained volunteer can give nursing care to a terminally ill patient- T/ F
2. Key players in community participation are\_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_ etc.
3. Facilitate affected families to get appropriate documentation to avail eligible social entitlements is the role of the MO- T/ F
4. Types of Community Participation are \_\_\_\_\_ and \_\_\_\_\_
5. The ASHA can identify community volunteers for palliative care T/F
6. The first step for mobilising community is treating palliative patients T/F



# EVALUATION-ANSWERS

1. Untrained volunteer can give nursing care to a terminally ill patient- **False**
2. Key players in community participation are **community volunteers, PHC workers (ASHA/MPW) families** etc.
3. Facilitating affected families to get appropriate documentation to avail eligible social entitlements is the role of the MO- **False. It is ASHA and MPW's role**
4. Types of Community Participation are **Helping through resources (money, manpower, time etc.) and Taking responsibility for identifying patients and caring for them**
4. The ASHA can identify community volunteers for palliative care **T/F**
5. The first step for mobilising community is treating palliative patients **T/F**  
**(Creating Awareness is the first step)**



# Thank You

