

# Compassionate Communities - Lessons from Kerala

Dr Suresh Kumar

Director

WHO Collaborating Centre for Building Country Capacity in Palliative Care and Long Term Care

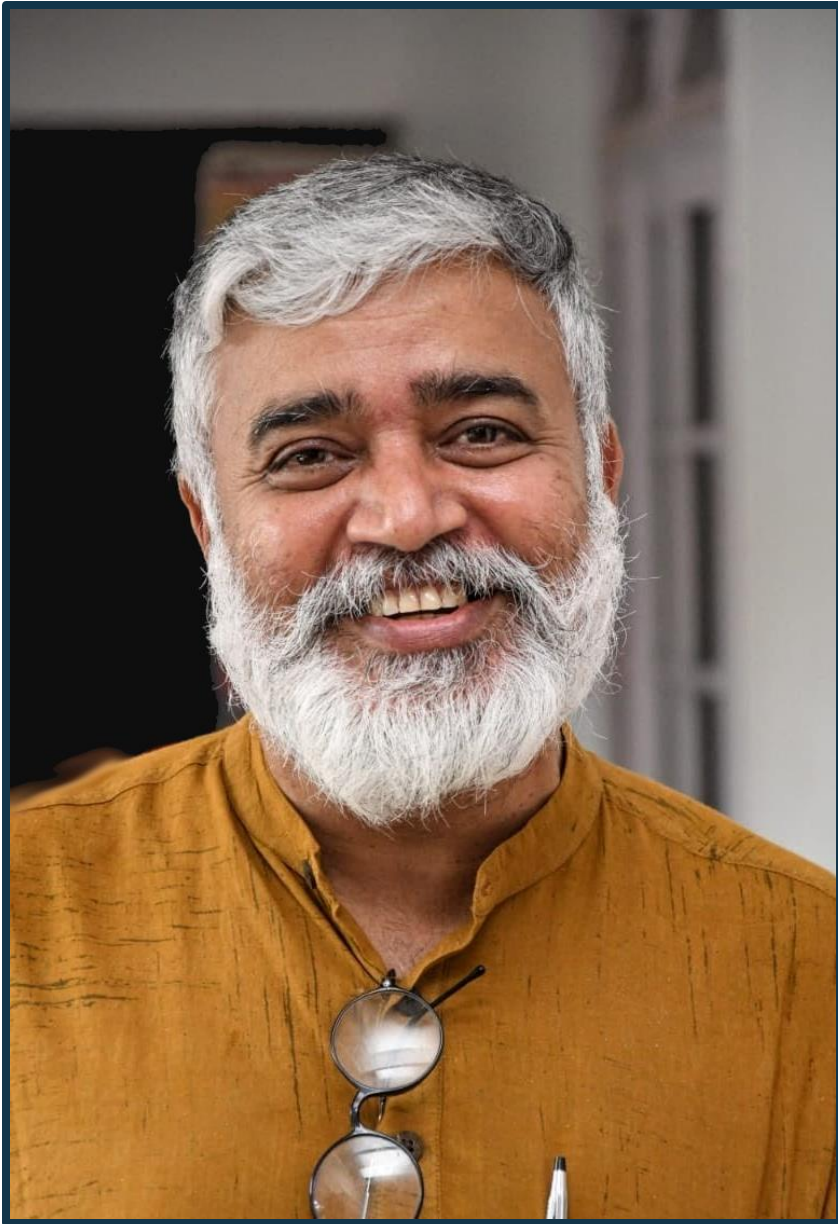


## 2025 PALLIATIVE CARE CONFERENCE

18 - 21 JUNE | DURBAN | SOUTH AFRICA

A COLLABORATION BY



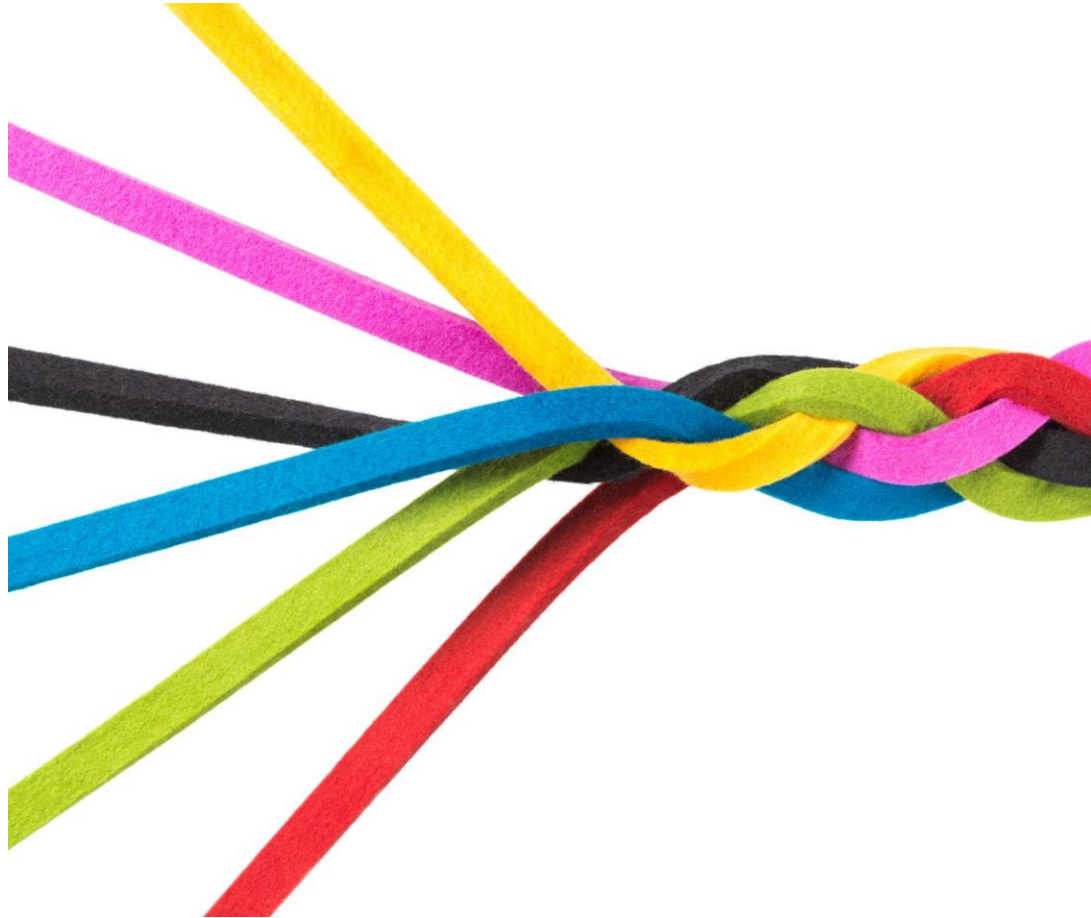


# Dr Suresh Kumar

Director, WHO Collaborating Centre

- Director WHOCC & Director Global Fellowship in Palliative Care
- Institute of Palliative Medicine
- Part of the core team, which established the community-based palliative care system in Kerala ( India)
- Active in Global Palliative Care scene for three decades

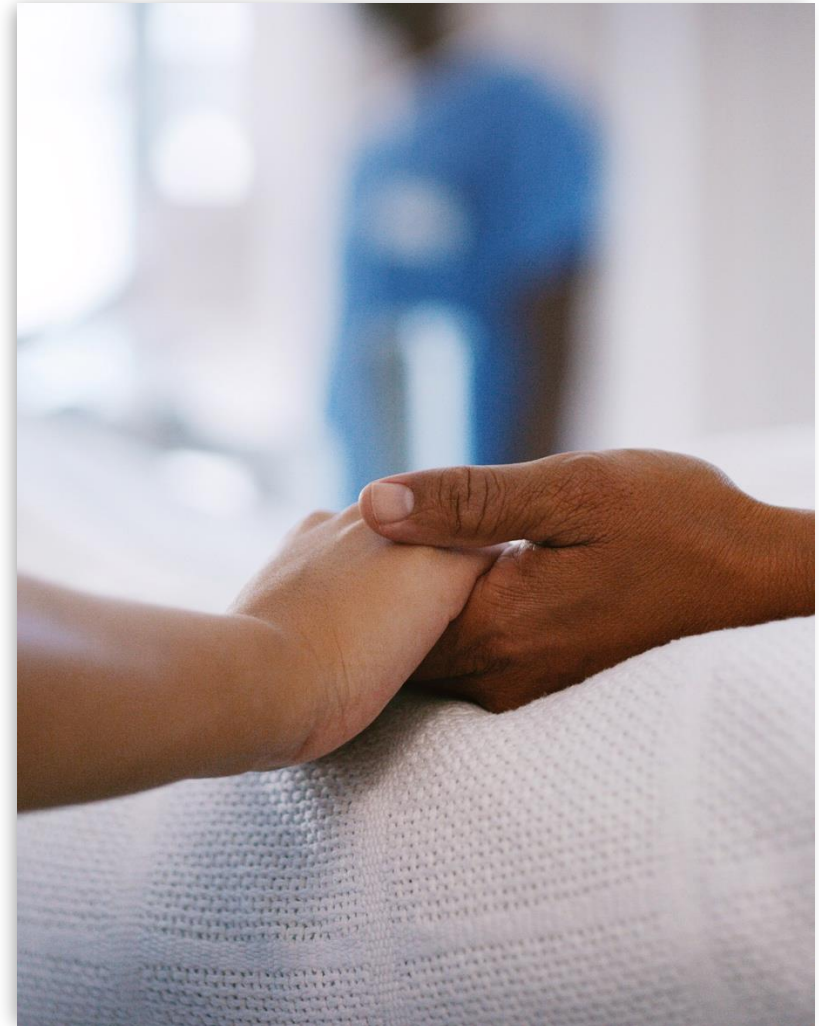
# Compassionate Community



A Compassionate Community is one in which people are motivated by compassion to take responsibility for and care for each other

# Compassionate Communities - Assumptions

1. Human beings are capable of supporting each other
2. Most of the communities still retain the ability to work together for common causes
3. Coming across a suffering person can trigger a sense of compassion in people
4. This sense of compassion can lead to sustainable, consolidated action in the community if proper platforms are available,
5. Such compassionate community participation can bring people solace and act as a powerful medium for learning and empowerment.



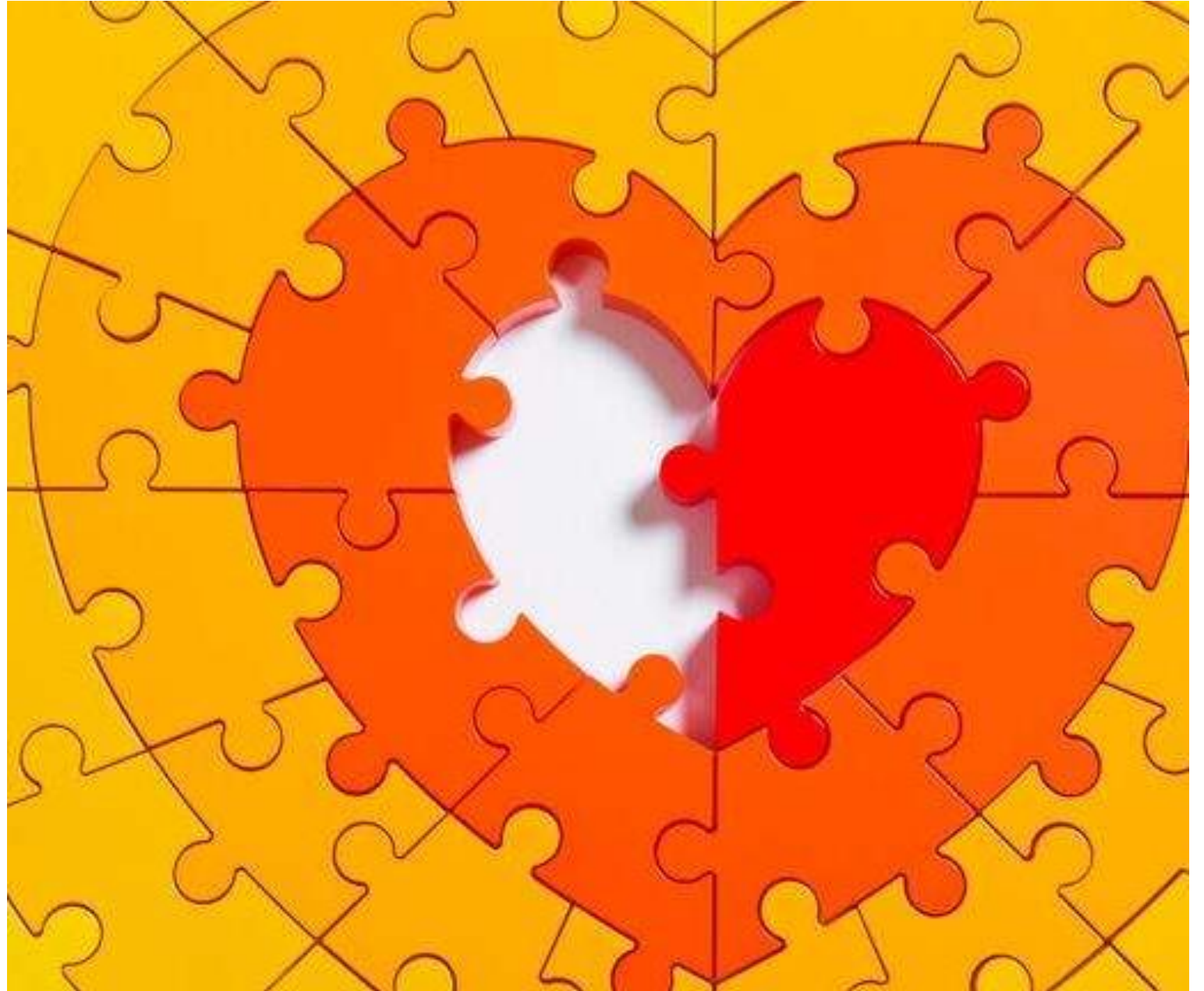
# Entry Point to the Compassionate Community Platform

Any activity for the marginalised people in the community can be the entry point to wider Compassionate Community Platform

- People at the End of Life
- Differently Abled
- Elderly
- People with Chronic Psychiatric illness

# Suffering at the end of life

People often suffer a lot at the end of their lives. A major part of this suffering is avoidable

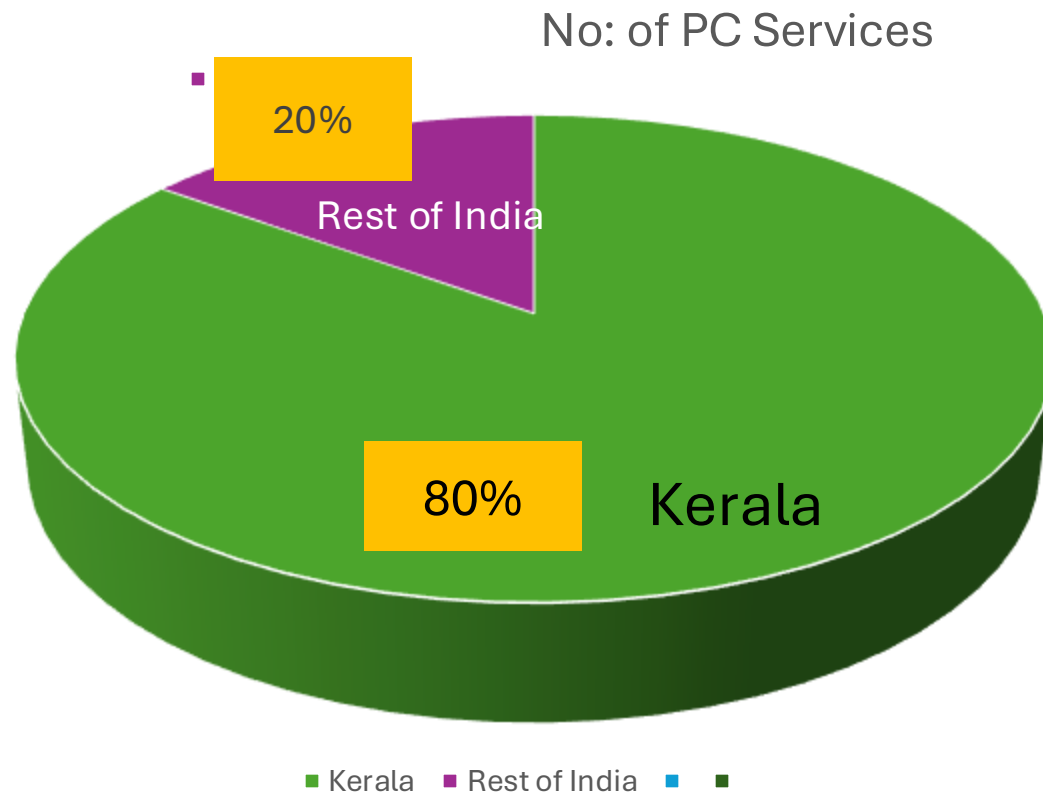


# Palliative Care - Rationale for intervention

Every human being  
has a right to live well  
with dignity

This right does not  
disappear when the  
person becomes  
incurably ill/ old/  
terminally ill/dying

# Palliative Care in Kerala



- Kerala in India
  - 1% Land area
  - 3% population
  - 80% of PC services in the country (1700/2200)
  - >70% coverage in palliative care as against the 3% nationally



## Volunteering in Palliative Care as an entry point to a compassionate Community

- Visible Suffering. Concrete entry point. Visible results
- Improving confidence to intervene in issues around death, dying and loss



# Kerala – What do we tell people?

## 1. Suffering at the end of life is a personal problem for all of us

We all have to die one day

Only 10-15 % of us will die suddenly

The rest of us will be bedridden and dependent on others for a period before we die

There is a lot of suffering associated with this phase which may last for days, months or years

Most of this suffering can be avoided if we have proper services, skills and knowledge

Only a small percentage of the needy have access to such services

Can we do something together to change this?

Can we learn?

Because it is a matter of personal concern to each one of us

Kerala – What do we tell people?

2.Addressing Suffering at the end of life is not just a medical issue

The 95% Rule: The patient spends 95% of his/ her time with family/ friends/ neighbours

Because suffering at the end of life has a huge element of non-clinical issues

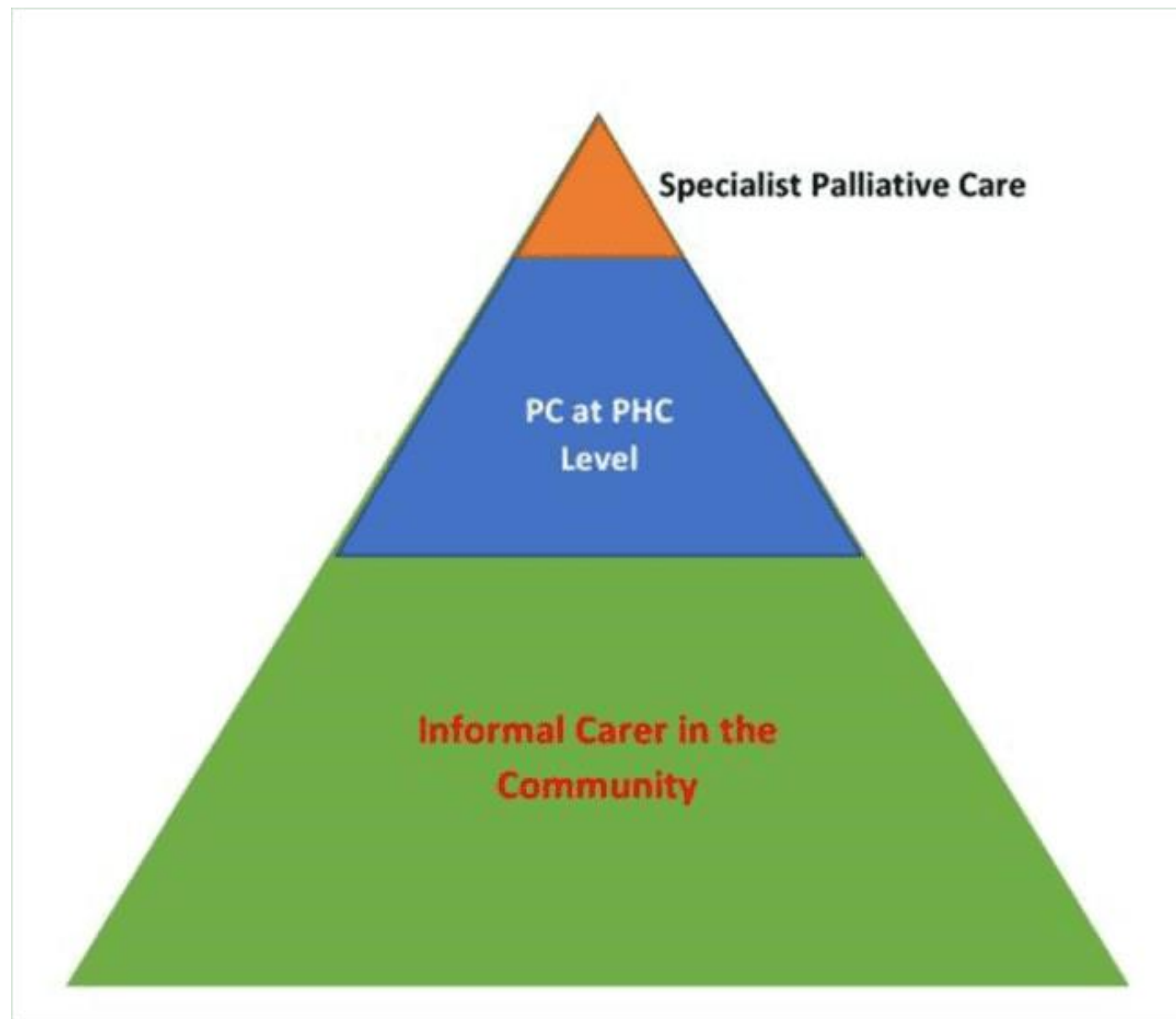
Incurable illness, Death, Dying and bereavement is a social, psychological and spiritual experiences with a medical component

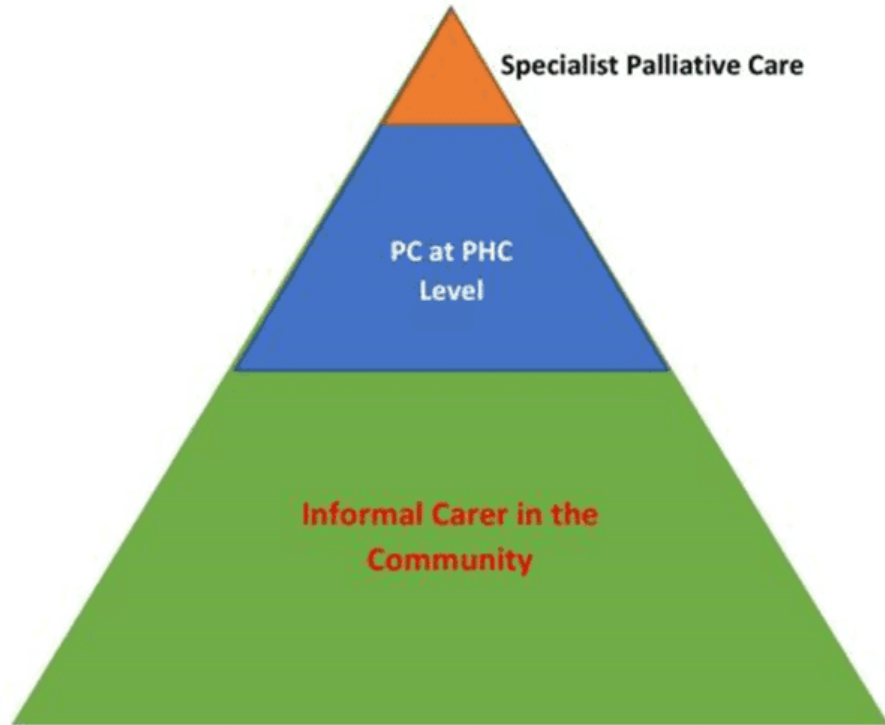
Healthcare needs to be seen not just as clinical services but also as the responsibility of all



The message: Palliative  
Care as everybody's  
business

# Palliative Care system in Kerala





## Bulk of Palliative Care services at the Primary Health Care level

- Development of community-owned home care services
- Capacity building at the primary healthcare level
  - Training
  - Drugs and equipment
- Integration between primary health care and community-owned services

# Kerala's Primary Palliative Care system

Universal Coverage at the Primary Health Care Level

> 1700 Palliative Home Care units (95% of palliative care home care units in India)

- > 1100 run by local governments
- >450 run by Civil Society Organisations
- >150 directly by Political parties

Integrated to the Primary Health Care system



# Key Players in Palliative Care in Kerala



## Local Governments

Primary Health Care System  
Social Welfare Systems

## Civil Society Organisations

## Religious Organizations

## Political Parties

# Inclusivity - Universal Access

Universal access to primary palliative care

Primary Care delivered through home care services

No cost to patients.

- The local government and the local community cover the cost of services.

# Local Government involvement

Guided by Palliative Care Policy of Government of Kerala

Taking the lead in administering grassroots-level palliative care programs

- Ensuring comprehensive coverage
- Basic clinical and social support services delivered at home
- Involving primary healthcare teams
- Ensuring community engagement

Coordinated single window for care delivery involving Primary Health Care, Social Welfare, and Community engagement components.

# Civil Society involvement in Palliative Care in Kerala

Broad and deep engagement by the community

Participation of trained volunteers in Local Government run programs

Non-Governmental service delivery programs run by

- Community groups
- Political parties

# Professional – Community Collaboration

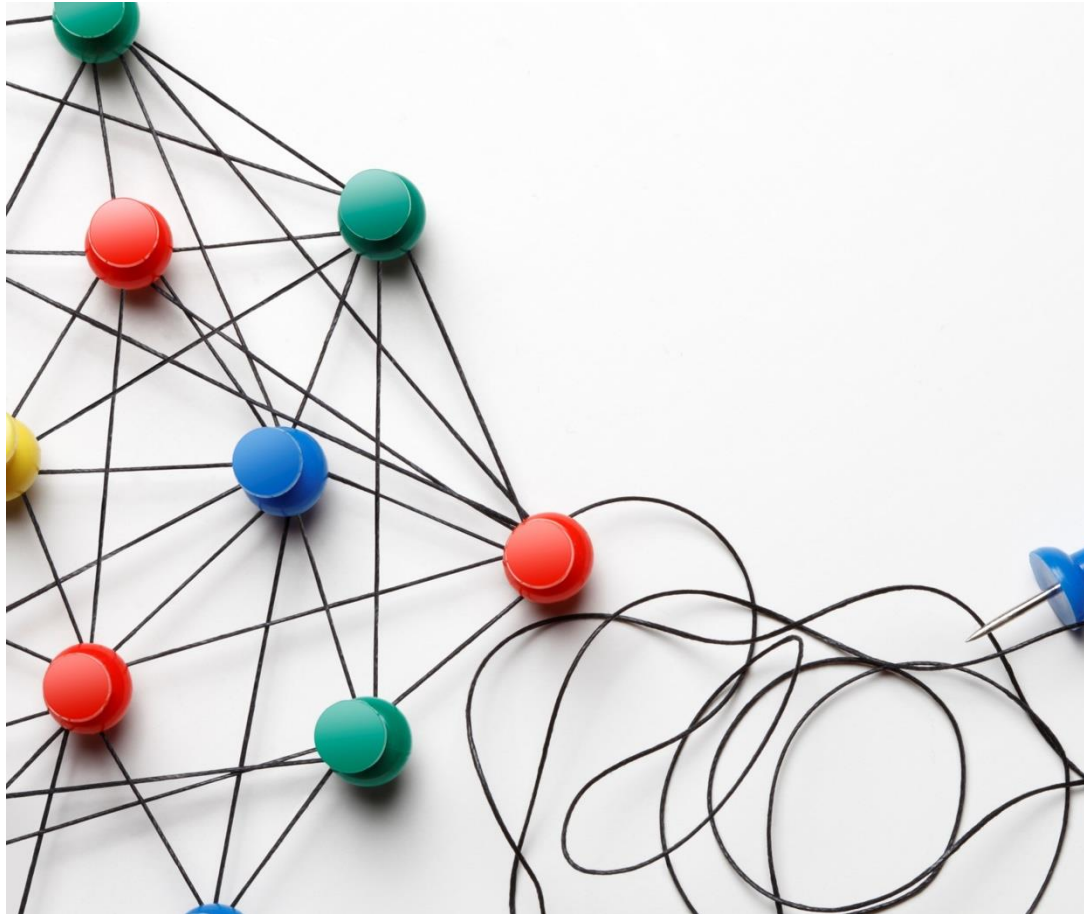
Healthcare professionals collaborate with trained community volunteers to provide holistic care for patients with advanced diseases.

Clinical care is primarily the responsibility of healthcare professionals

Psycho-social and spiritual support handled by trained community volunteers.

- Structured training in palliative care
- Organization into groups
- Runs own palliative care units or works with LSGL-led units

# Community Programs in Palliative Care in Kerala— What did we basically do?



- Strengthen the informal caring system; ensure its role and sustainability
  - Networking
  - Capacity building
  - Orientation

# Strategy: Encouraging capacity building in the community

- All of us see death, dying, old age and advanced diseases around us
- Patients with advanced illness spend >95% of their time in the company of family members, friends and neighbours
- People visit/ support family members/ friends/neighbours when they are bedridden/ dying
- The time spent can help address suffering if the visitor knows how to talk to the patient/ family and how to help them
- Necessary skills and knowledge can be acquired through training




# Community Participation System

## Empowering the community to

- Create a **sustained** supportive environment for people with advanced disease, the elderly and the dying
  - Transform episodic efforts for occasional patients to a sustained system
- Make sure that people do not feel isolated and helpless
- Death Literacy – build awareness that death and dying are part of life

Orienting the formal health care and social support system to work with the community



# Lessons from Kerala- Steps in Building a Community Program

---

---

Orienting the Health Care & Social Welfare system

---

Sensitization of the community

---

Defining roles and responsibilities

---

Training for the community

---

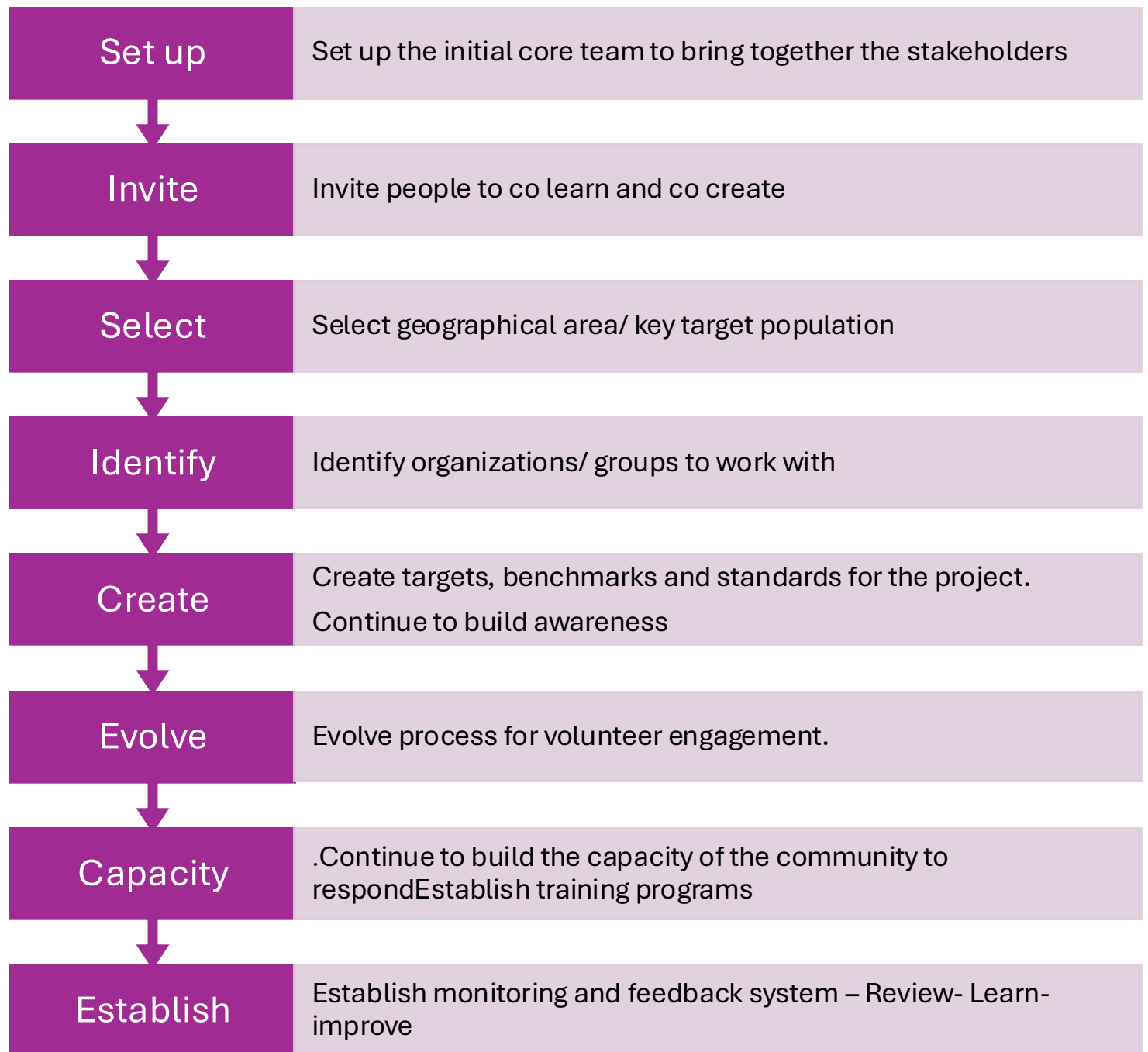
Starting a pilot project

---

Setting up the audit cycle for evaluation and improvement

---

# Involving the community in the Compassionate Project in Palliative Care – Eight Steps



# Thank You!

[drsureshkumar@gmail.com](mailto:drsureshkumar@gmail.com)

