

# Are we agreed on our goal?

Relief from serious health-related suffering(SHS)  
and improvement of quality of life.

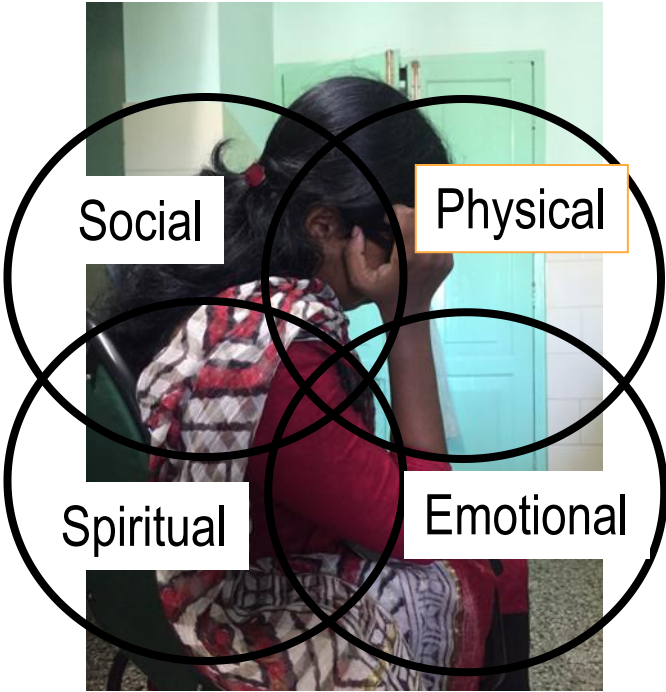
Not only for cancer. For any disease.

Not only for end of life.

Across continuum of disease.

The Lancet 2017; 391:10128 [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)32513-8/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32513-8/fulltext)

# Elements of health-related suffering



# We need to go as deep as possible

Surface  
work

Depth  
work



# The patient at the centre

## The family around him/her

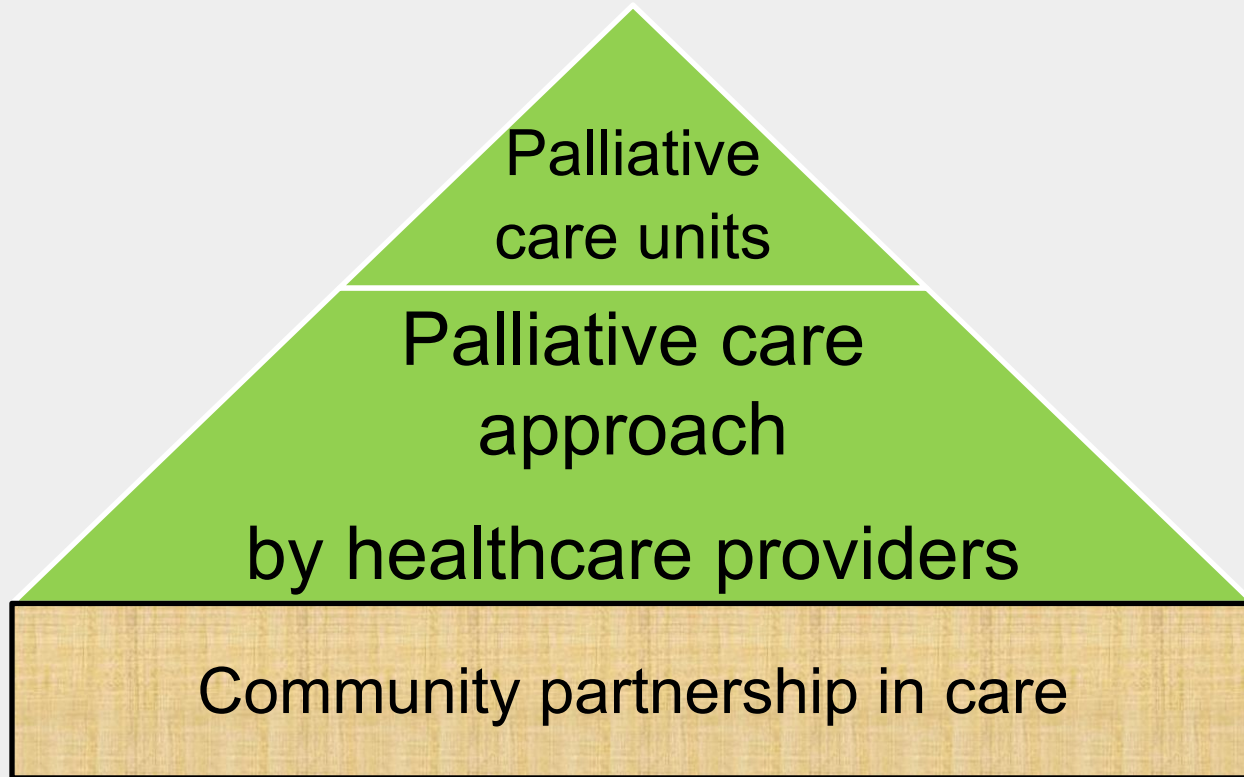


<https://palliumindia.org/pallium-india>

# Team members

- **Family & other Care-givers**
- **Volunteers**
- Doctors
- Nurses
- Pharmacists
- Social workers
- Physiotherapist
- Bereavement counsellors

Anyone who can contribute to **quality of life of the patient and the family.**



# The heart of community participation:

**He aha te mea nui o te ao**

**He tangata, he tangata, he tangata**

What is the most important thing in the world?

It is the people, it is the people, it is the people.



*Maori proverb*

# Clarity in terms

- Community outreach





# What is community-based?

The community is **consulted and involved** to improve access to health services  
And programs by interventions  
inside the community  
with necessary professional support.



WHO 2016. <https://www.who.int/publications/i/item/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers>

# Defining core values

- Patient & family at centre; not the organisation
- Care is a right; not charity
- Compassion AND competence
- Respect; dignity
- Autonomy; beneficence; non-maleficence, justice



# Community participation – Challenge 1: Closed doors of healthcare systems

- Legal & procedural barriers
- Resistance to change
  - Fear (Will they dictate terms to us?)
  - Anger (I have medical degree; how dare they question me?)



# Steps in community participation

1. Professionals' acceptance
2. Public awareness programs
3. Recruitment of volunteers
4. Training program for volunteers
5. Launching the program
6. Periodic evaluation, review & course correction

# Community participation - Challenges

- Closed doors of healthcare systems
- Vested interests of participants
  - Personal (power; money, ego)
  - Political
  - Religious
- Quality of care diluted?
  - Values; ethics?

