The Involvement of the Community: Palliative Care in India
Palliative Care: Current Indian Context

- 100 million elderly population
- 0.7 million new cancer patients a year
- 6 million needing palliative care a year
- Only 2% have access to palliative care
- Grossly inadequate palliative care, including Opioid analgesics
Palliative Care: Current Indian Context

- Around 900 palliative care units
  - 93% located in Kerala
- Only 249 facilities have license and trained personnel to provide Opioid analgesics
  - 74% located in Kerala
Palliative Care: Current Indian Context

- Growing commercialization of health care
- Around 80% of healthcare expenses are out-of-pocket
- Catastrophic Health Events push families into debt
- Growing tendency to exploit the sick and the dying
- Families shoulder responsibility of the terminally ill
Palliative Care: Current Indian Context

- Most of the palliative care initiatives focus mainly on pain management
- Need for a holistic palliative care approach, including pain management and Care for the Caregivers
Leading Entities

- Pallium India
- Neighbourhood Network in Palliative Care (NNPC), Kerala
- MNJ, Hyderabad and other Regional Centres
- Indian Association of Palliative Care (IAPC)
- Over 100 palliative care initiatives in the CHAI network
Sr. Dr. Mary Glowrey

- Born in 1887, Victoria, Australia
- Graduated from UoM, in 1910
- Worked in Australia for 10 years
- Reached India in 1920
- Established CHAI in 1943 along with 16 companions
75 years of service to the Nation
largest not-for-profit health care network in India

- 3553 Member Institutions across the country.
- 90% of them are headed by women religious,
- 80% of them in remote medically underserved areas,
- Operating under 11 Regional Units across the country.
The Catholic Health Association of India

- **1,000** Sister Doctors
- **25,000** Sister-Nurses
- **10,000** Sister-Paramedicals
- **5,000** Sister-Social Workers
- Large number of lay professionals
Challenges in Palliative care

- Too many people to be cared for
- Multicultural-linguistic-religious-socio-economic context
- Lack of trained & committed personal
- Caring for the caregivers – burn out
- Commercialization of Healthcare & growing tendency to exploit the dying
- Financial resources
Project Title - “Pratyasha (a ray of hope) - Holistic Palliative Care centers for terminally ill patients”
Pratyasha – A Ray of Hope
Sharing the fullness of life ...
Adding life to days ...
Pratyasha – Guiding principles

• Palliative and End-of-Life Care
• Pain management
• Whole person approach
• Pratyasha homes
• Joyful transition
• Rediscovering hope
• Care for the Caregivers
• Bereavement support
Pratyasha – Guiding Principles

• Embedded in neighboring communities
• *Ecclesia optics (come and see): Bi-directional Dynamics*
• Volunteerism - Local community elders, youth, students, religious leaders, PRIs & Other Govt. Line Depts.
• SBCC & social transformation
Pratyasha – in action
Pratyasha - Leveraging the healing power of Nature

Catering also to the senses: smell, taste, sound, touch, and sight

- Seasonal-fruit and vegetable gardens
- Greenish and flowery Indoor plantation
- Water bodies (sound of water flowing), aquariums
- Pet garden: meant for pet therapy
- Soothing Music
Pratyasha – Holistic Therapies

- **Biblio-therapy** – books & audios & videos - inculcating positive thinking & meaning in life,

- **Art Therapy** – encouraging patients and caregivers for free self-expression through painting, drawing, clay modeling, etc.

- **Counselling** - Group sharing; Individual Counseling for patients and close caregivers

- **Prayer**
Pratyasha – Centre of Excellence, Hyderabad

- Holistic care – 25 beds
- Training – CTC; Online (Pallium India, two worlds, Misereor, CEI)
- Research (UoM, St Vincent’s health)
- Advocacy (influencing policies & tapping resources)
Pratyasha – National Movement

- CHAI Network - the reach, the numbers, grass roots presence, potential for social impact
- Hub & Spoke Model with Pratyasha homes
- Simple existing infrastructure
- Standardized care