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PALLIATIVE CARE

POLICY AND FINANCIAL PERSPECTIVE

Fr. Thomas Vaikathuparambil

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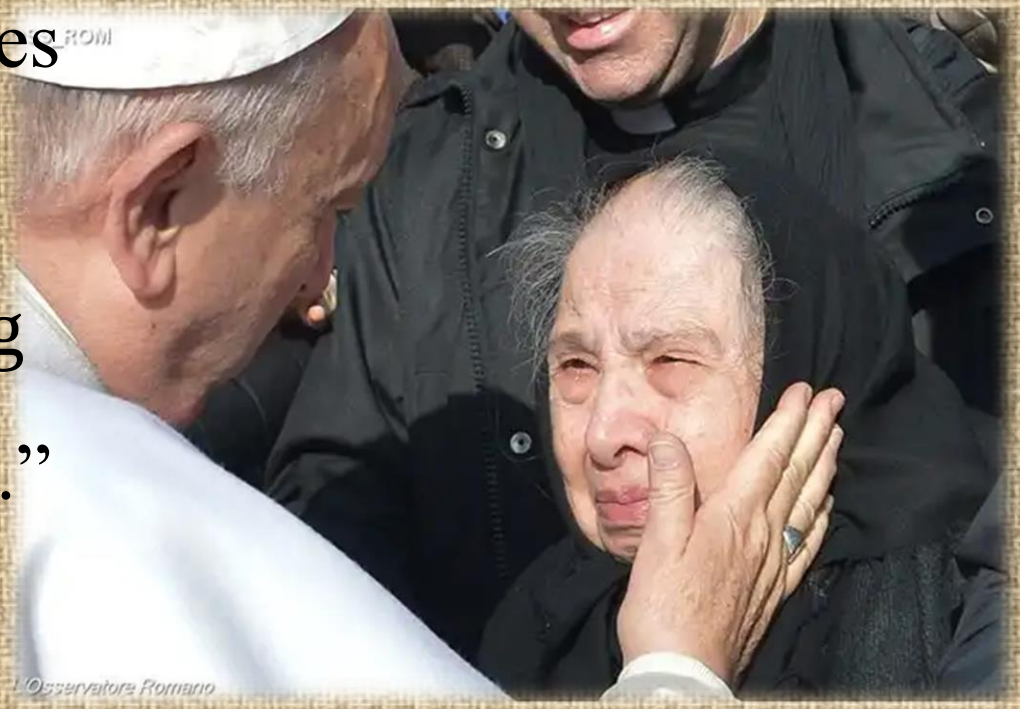
"PALLING UP FOR PALLIATIVE CARE"

"Palliative care recognizes something equally important: recognizing the value of the person."

- POPE FRANCIS



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TOPICS AT A GLANCE

1 Pain And Palliative Care Policy

2 Catholic Church And Palliative Care

3 Lisie Hospital' S Experience In Palliative Care

4 Financial Perspective

5 Future Of Palliative Care

6 What Can Countries [Govts] Do

7 What Can Church Do

8 What Can We Do At Grassroot Level

9 Conclusion

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1-PAIN AND PALLIATIVE CARE POLICY

- Any health policy is influenced by the Nation's Demography, Political - Economic background , Financial Scenario and Priorities.
- Even within a Nation (with different states), State to State level Social-Political-Economical inequalities prevail.
- However some basic facts have to be borne in mind while framing policies esp. for Palliative care.

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Palliative Care development follows a Public Health Model developed by the WHO that emphasises;

- **Policy,**
- Education,
- Medication Availability,
- and Implementation.

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CONSIDER THE FOLLOWING WHILE FRAMING POLICIES:

- Medical care and support must be provided to every citizen in need of palliative care.
- There must be community-based approach to healthcare and home-based medical care must be the cornerstone of palliative care services.

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- Any National Palliative Care Policy should be aligned with the WHO Six Core Components (Building Blocks) of Health Systems:
    i. Leadership/governance;
    ii. Service delivery;
    iii. Health workforce;
    iv. Health information systems;
    v. Access to essential medicines,
    vi. Financing

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- Three measures are recommended as a foundation for developing palliative care in any country /state through the public health approach
  - Government Policy
  - Educational Policy
  - Drug Policy

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i. **A GOVERNMENT POLICY** to ensure the integration of palliative care services into the structure and financing of the national health-care system

ii. **AN EDUCATIONAL POLICY** to provide support for the training of health-care professionals, volunteers and the public

iii. **A DRUG POLICY** to ensure the availability of essential drugs for the management of pain and other symptoms and psychological distress, in particular, opioid analgesics for pain relief.

All three of these measures are necessary, along with committed leadership, to achieve an effective palliative care programme.

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2- CATHOLIC CHURCH AND PALLIATIVE CARE

Of the six WHO core components of health systems,

HEALTH WORKFORCE is a very important component.

- Roman Catholic Church is the largest non-government provider of Health Care Services in the world with largest health work force
- for Eg. the Catholic Health Association of India (CHAI) is the largest non-government health care network in India

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- Long before the concept of Palliative Care came into vogue, the Catholic Institutions all over the world were taking care of geriatric , sick and terminally ill patients without discrimination on the basis of place , race, caste, creed or religion.
- Their service was devoid of publicity
- In Indian health scenario, more than70% of health care services provided by Private Health Care Centers and Hospitals.

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3- PALLIATIVE CARE IN LISIE HOSPITAL

- Lisie Hospital, a charitable institution of the Archdiocese of Ernakulam-Angamaly, located in Kerala state, South India, is the living expression of the Apostolic concern and social responsibility.
- Holding the motto “Care with Love” close to our hearts, we accomplish our mission of “providing high quality treatment of global standard for all and at affordable cost for the less privileged irrespective of caste and creed”.

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IN LISIE MODEL THERE IS NO ESCALATION OF COSTS

Even in this era were Health Care Services are being elevated to a concept of Health Care Industry with profit motives, we uphold the following;

- We do not have profit motive
- We do not have a profit making marketing strategies such as products or service promotions and advertisements
- The patients are our billboards

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- Lisie Hospital is the pioneer in health care services offering refuge of people who cannot afford to go to the expensive corporate hospitals, for the last 62years.
- A team of dedicated doctors and staff run the Pain and Palliative clinic in our hospital.

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LISIE HOSPITAL PALLIATIVE CARE POLICY : UNIQUE MODEL

1. Free OP, IP and Homecare to all BPL [Below Poverty Line] Palliative Patients
2. Counselling service and Spiritual support to the patients as well as to the family
3. Preparing for a peaceful end of the life
4. Patient-friendly environment
5. A group of well trained volunteers provide service to the patients, from the vicinity of the hospital area and give regular feedback .

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OUR WELFARE PROGRAM

- Caritas India is a society registered under the Societies Registration Act, founded in 1962, which is the official development arm of the Catholic Church's in India.
- Caritas India is the member of the Caritas confederation working in nearly 200 countries making it the second largest humanitarian network in the world.
- In India CARITAS INDIA is training **26,000 VOLUNTEERS** for palliative care all over the country the project named as ASHA KIRANAM
- It is a comprehensive project for prevention [identify causes and take preventive steps] and care of cancer.
- Lisie Hospital has signed an MOU with Caritas India to train the volunteers for Palliative care.

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ASHAKIRANAM – Strategies

Prevention - Awareness/Education

Early detection – screening

Proper and adequate treatment

Good food

Palliation

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Concerns

- Lack of Facility
- Lack of Awareness
- Misconceptions/ Myths
- Lack of Health Education
- Chemicalised Food Intakes
- Lifestyles And Practices
- Lack of Fund - The Health Policy
- Lack of Support System Eg. Palliative

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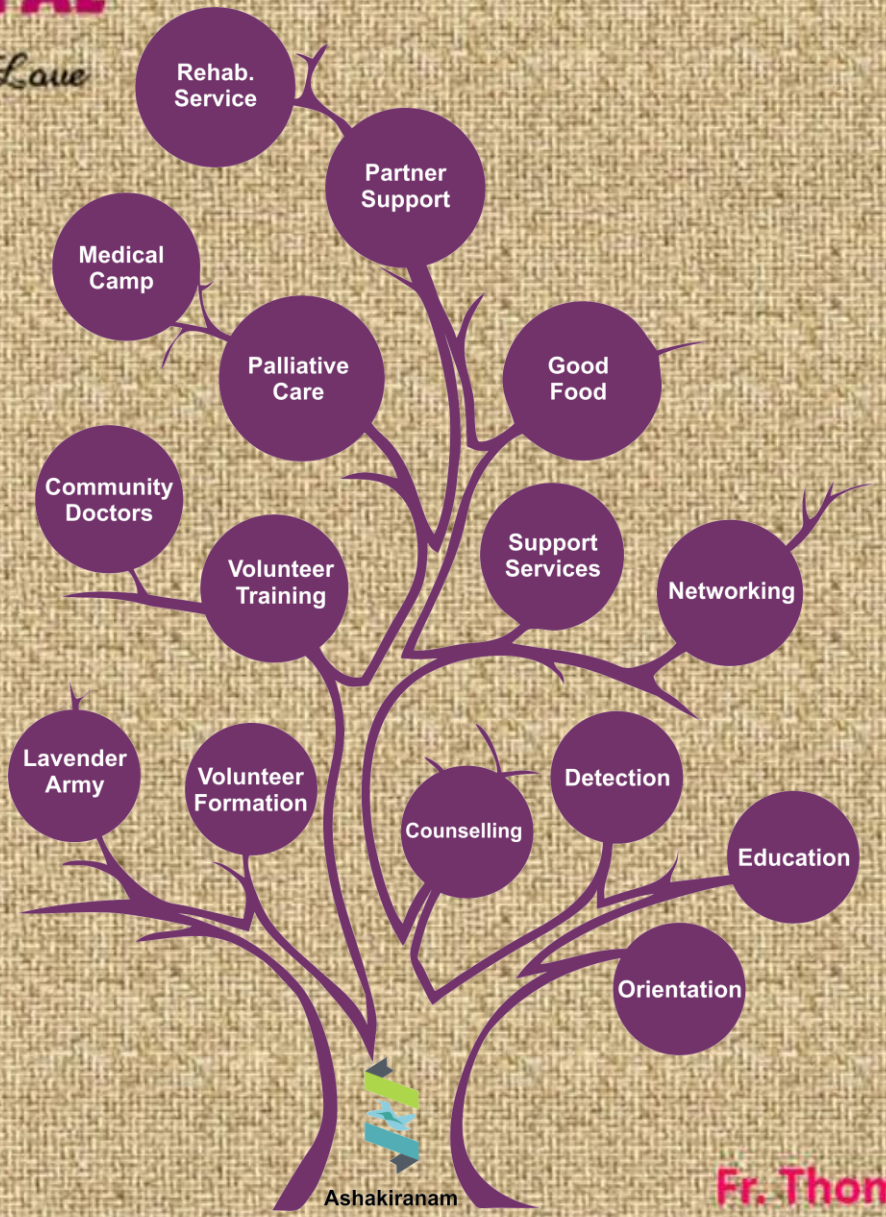
PROGRAM TREE



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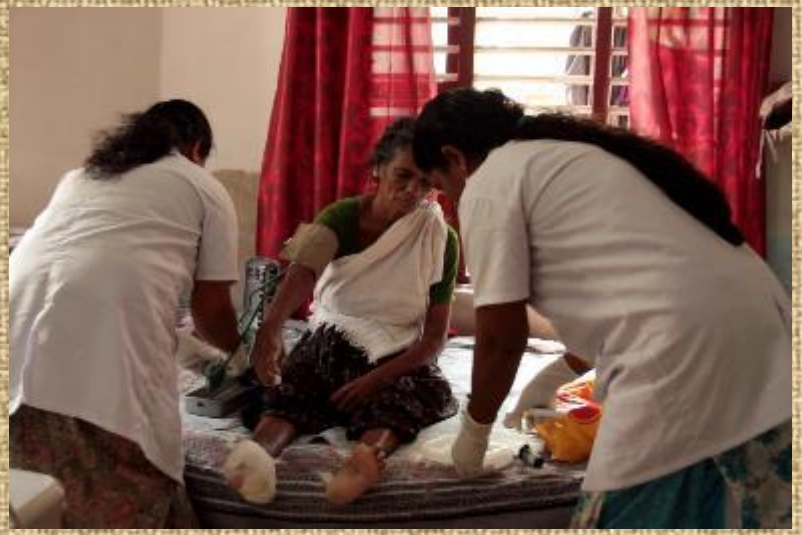
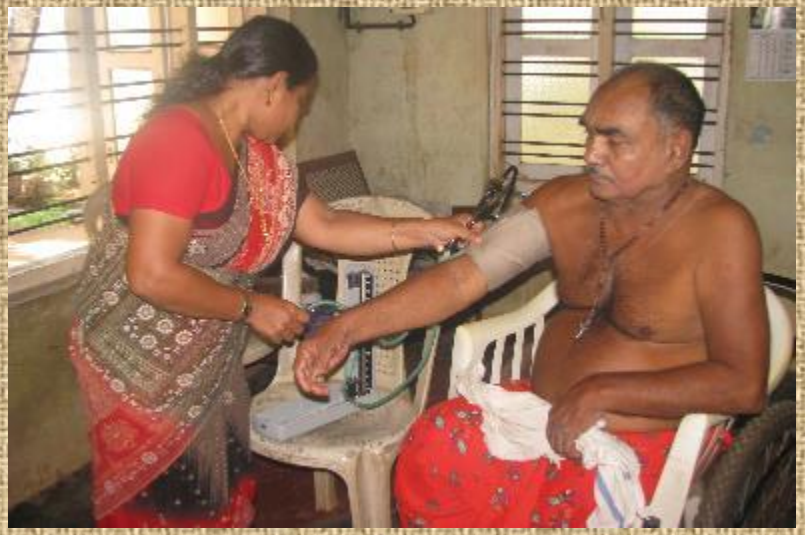
Counselling



Medical Management



Occupational Therapy

Social integration & Rehabilitation

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A NEW PARTNERSHIP

Caritas India & Lisie Hospital

- Social Mobilisation for Prevention
- Technical Support for Education
- Training for Palliative Providers
- 20 Thousand Community Doctors in Five Years
- Outreach Services in three Central Districts of Kerala

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OUR EDUCATIONAL POLICY

- The Concept of Palliative Care is not part the curriculum of INC (Indian Nursing Council) and MCI (Medical Council of India).
- Considering the importance of Palliative Care Services we are starting **Palliative Care Nursing Education Programme** to enable nurses to get trained in palliative care – this will help improve the state of palliative care services at community level.
- For the past 56 years Lisie Medical and Educational Institutions have molded a considerably large number of nursing and para medical professionals, who have now grown to a state of catering medical services in countries all around the world spreading the core values of Lisie Hospital.

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LISIE PHARMACEUTICALS

- Lisie Hospital Pharmaceuticals, established in the year 1970, is the one and only unit in Kerala which has the license to produce and supply narcotic drugs, to all hospitals in the state and also few neighboring states.
- The institute aims to manufacture and supply quality ensured drug products to the poor and suffering people at affordable price.
- This unit was approved by the drug controller for the manufacture of Narcotic Drugs like Pethidine, Morphine And Fentanyl Citrate.
- Opioid analgesics are the mainstay of palliative care.

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- Around 30 to 50 lakh tablets and 1 lakh vials per month is being supplied from our unit.
- There has been no shortage of morphine till date.
- We have a license to hold 100 kg of opium, the raw material to make pethidine and other opiods
- We also have a license to hold 100 kg of morphine
- [Kidwai Hospital, neighboring state gets only 15kg of morphine per year]

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We also produce and distribute various other drugs and Haemodialysis fluids to selected hospitals at very low cost.

- Govt. fixed the price at Rs.4/- But we give the medicines for Rs 1.10/-.
- We have not increased the price significantly for the past 20-30 years
- A patch of Fentanyl costs Rs 300/. Which is beyond the reach of poor patients

- We are proud to say that our support helped our state [Kerala] grow as a role model to the entire developing countries in Palliative Care
- This model can be replicated in developing countries

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4-FINANCIAL PERSPECTIVE

Palliative care funding can be;

A. Part of the **MAIN FUNDING SYSTEM**, social security or universal coverage system of a country (*Financial Burden to the Nation*)

B. **OUT-OF-POCKET** payments system (*Financial burden to patient or his/her family*)

C. Mixed of the above two (*co-payment system*)

D. Rely on **CHARITABLE FUNDS**

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CHALLENGES IN FINANCING PALLIATIVE CARE

- Problem of population especially in developing countries.
- Scarcity of resources
- Twin burden of diseases: continuing & emerging infections +chronic degenerative disease
- Socio-economic inequalities
- Inadequate & inequitable distribution of workforce
- Financial neglect & political neglect
- Increased burden of disease : poor social infrastructural development poor nutritional status, low literacy level, lack of safe drinking water & sanitation

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5-FUTURE OF PALLIATIVE CARE

- The future is going to witness a 'PALLIATIVE CARE EXPLOSION' as far as its requirement is concerned.
- An increasing proportion of older people, rising incidence of cancer as well as cancer afflicted living longer, and above all recognition of supportive and symptomatic care requirement explains this explosion of need.

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6-WHAT CAN COUNTRIES [GOVTS] DO OR WHAT DO WE WANT FROM GOVT.

As discussed earlier apart from policy framing and implementation;

- Govt should include Palliative Care into the educational curriculum of Medical, Nursing, Pharmacy and Social Work Courses.
- Govt should refine the Legal and Regulatory system to improve access to Opioids for pain relief.
- Measures for primary prevention must receive more attention

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7 -WHAT CAN CHURCH / NGO'S DO

The Church / NGO's can contribute in;

- Giving training
- Supporting the caregivers/family members to provide maximum home-based care
- Sensitizing and educating the public against stigma and discrimination of the sick elderly
- Promoting the utilization of modern technology, for instance, training frontline health workers in telemedicine, thereby making quality health care for the elderly more accessible and affordable, especially in the rural areas
- Youth can be trained for palliative care and many catholic youth are serve as volunteers.

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8 -WHAT CAN WE DO [AT GRASS ROOT LEVEL]

How can we reduce cost of palliative care

- The need of the hour is to create awareness about palliative care among public, through various medias, internet and health education materials .
- Awareness and knowledge about palliative care is essential to lower the cost of palliative care
- Moreover this awareness is also needed to access various government schemes and benefits.

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ASHA – ACCREDITED SOCIAL HEALTH ACTIVIST

- In India we have ASHA workers who work at the grass root levels providing health care services to the needy
- Most of the villages in the country is provided with a trained Female Community Health Activist from the village itself.
- They identify patients who need palliative care and patients who are eligible for the pensions /benefits given by govt.
- Changing the setting of care for a patient at the end of life from hospital based to community based has the potential to reduce the daily cost of care .
- Reducing hospital stay saves cost of palliative care .

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- A 24 HOUR HELP LINE to assist people to get through palliative care can be proposed so that instead of bringing the patient to hospital, instructions are given over phone and instructions are carried out by the caregiver at home
- More people from general population must join as volunteers
  - Volunteers are an integral part of palliative care .
  - They play a vital role in bringing down the cost of palliative care.
  - They help reduce the cost of palliative care by providing Services, Medicines, Equipments, Vehicles and Monetary help.

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NEIGHBORHOOD NETWORK IN PALLIATIVE CARE [NNPC]

The Neighborhood Network in Palliative Care (NNPC) is a;

- Community-led initiative aiming to provide Home-based palliative care to all those in need in Kerala, South India
- In this programme, volunteers from the local community are trained to identify problems of the chronically ill in their area and
- To intervene effectively with active support from a network of trained professionals.

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- The project has brought together people from all walks of life on a common platform of working for the chronically ill.
- The youth raise money by working during their free time or on weekends
- They work as caterers or stage decorators in marriage halls
- The money they receive is pooled for palliative care
- The volunteers also help the caregivers who cannot go out and work to find a sustainable source of livelihood.
- Facilities are provided to sell their products.
- Trade fairs are conducted once in a while and profit is given for palliative care.

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- Volunteers [especially youth] help in rehabilitation of patients.
- Computer training and training for making art from waste are imparted by these volunteers themselves
- Volunteers conduct get together of patients.
- They take the responsibility of bringing the patients to the meeting place, giving food, arranging cultural programmes and helping them return to their respective houses.
- These volunteers help in getting sponsors for these patients.

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- Medicines and food kits are sponsored for the needy families on a long term basis
- It is these volunteers who serve as a link between the sponsors and the deserving patients.
- It has been shown that when the neighbourhood groups are in charge of the programmes, both expansion and achievement of financial sustainability happen quickly.
- It helps the local communities to be in full charge of the initiatives.

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9-CONCLUSION

- We are already facing barriers of need-supply deficit and unequal distribution
- We are entering a 'PALLIATIVE CARE ERA'.
- For effectively going ahead it is of utmost importance to integrate palliative care into medical education, healthcare system, and societal framework
- What is required to revolutionize palliative care is a 'Think personal, Act global' thinking, that is,
- Policy makers, stake holders, and health professionals' realization
- that what care or services they would like to receive for themselves and their relatives in ill-health, take them as a standard of care, and pledge to provide the same to everyone globally, so that we achieve our goal
- PALLIATIVE CARE:EVERYWHERE & BY EVERYONE

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- Mary Callaway mcallaway@sorosny.orgFunding Hospice and Palliative Care Internationally: The Funder's Perspective Mary V. Callaway Director, International Palliative Care Initiative Open Society Institute EAPC Vienna Congress May 2009
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I thank

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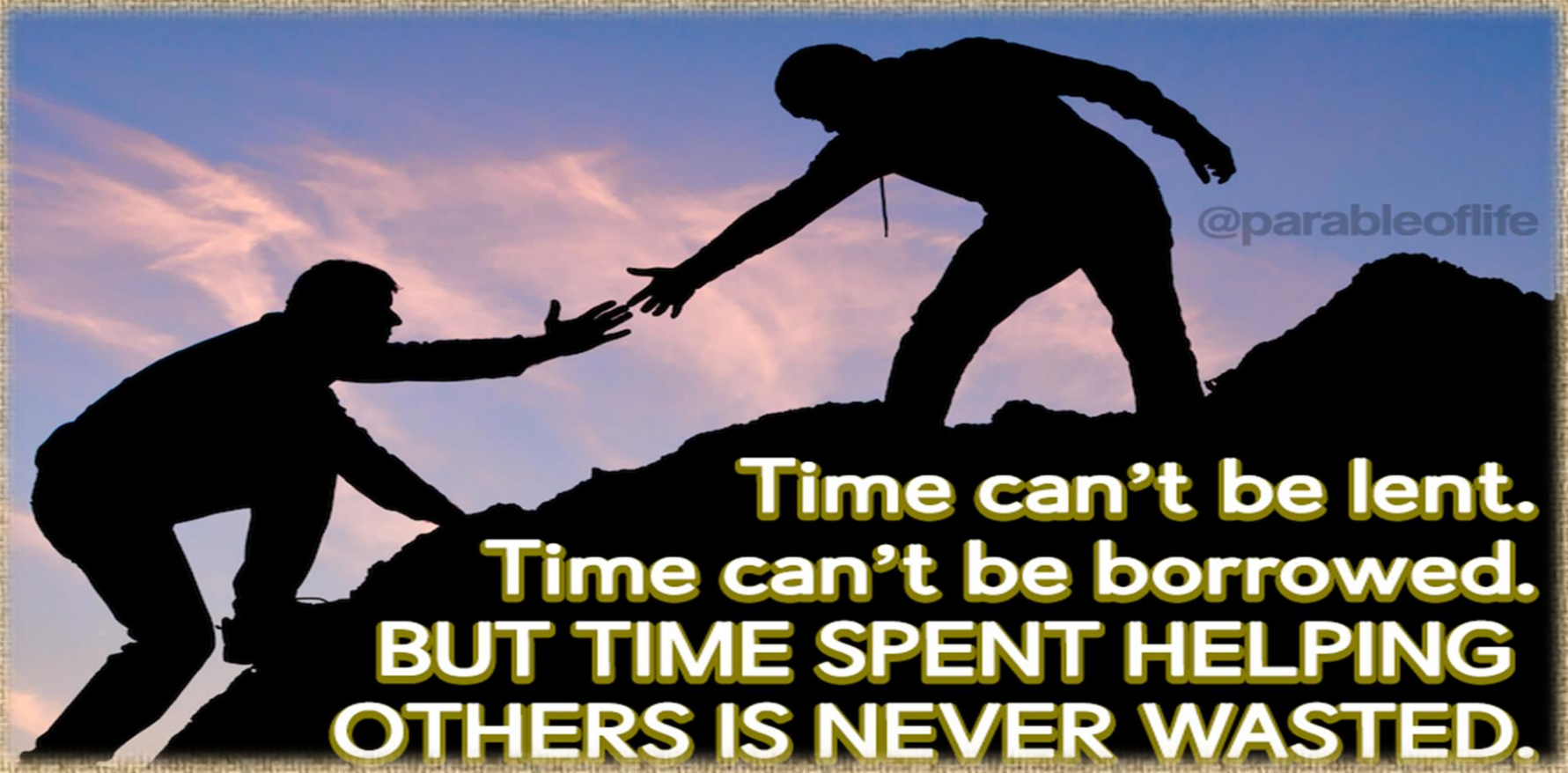
Thank You



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