

# Helping the Helpers to provide better help for dementia patients in India

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# Alzheimer's disease shall be an epidemic by 2030

- In India, around three per cent of rural population and almost five per cent of urban population above 65 years of age, suffer from Alzheimer's disease, characterized by progressive memory degeneration.
- On the occasion of the World Alzheimer's Day (September 21), medical experts opined that by 2030 there may be an “epidemic” of Alzheimer's disease.
- A recent survey indicates that with 42-crore Alzheimer's patients, India is poised to overtake the United States in this category.

# Indian Scenario vs Western Scenario

- Unlike in western countries, India lacks organized dementia (memory disorder) centers/hospitals/caregiver organization to deal with such a large dementia population.
- Unlike in western countries, most Indians lack medical insurance and patients/caregivers pay out of pocket for medical care.

# Indian Scenario vs Western Scenario

- Unlike West, India lacks specialized nursing homes and day care centers to care for patients with dementia.
- In the absence of government funded centers most dementia patients are cared for at home by family members (caregivers).

# The dementia patient and caregiver

- It is unclear how much dementia patients are aware of their disorder and suffering as the disease advances.
- Caregiver pain and suffering is immense.
- Not infrequently this leads to caregiver physical and mental burnout as caring for these patients is a 24/7 commitment.
- Even the most dedicated of caregivers are not immune from this burnout.

# Small towns vs Big cities

- In India especially in small towns and cities, joint family system still thrives.
- In these large families, many caregivers are able to look after the dementia patient by division of labor.
- For many in these large families, taking care of the elderly family member is an ingrained tradition.

# Small towns vs Big cities

- In big cities, nuclear families are the norm.
- As the family size shrinks, the burden of care of the demented patient falls on the spouse.
- In spite of desire and determination, the spouse may be unable to shoulder this burden 24/7
- In many cases, the caregiver spouse has to also work outside home to support the family income including medical care expenses.

# Caregivers desperately seek help

- Nine years ago, I went on a house visit to see a patient suffering from Parkinson's disease with dementia (PDD).
- His wife tearfully confided in me that a young man whom she had employed as a caregiver was threatening to leave, unless provided with tea and snacks every 2 hours in addition to his wages. Without his help, it would be impossible for her to move her husband, change his clothes, bathe and assist him with his toilet needs.

# Story of *Kamla*

- I first met Kamla when she was looking after one of my patient disabled and bed ridden with a neurological condition.
- Her dedication & devotion to my patient impressed me.
- When the patient passed away, Kamla reached out to me for a job.
- A senior colleague had brought his mother-in-law from England. She was suffering from dementia and I recommended Kamla to them. Kamla remained devoted and attached to the old lady. After her death, Kamla too passed away a month later.

*DEDICATED HELPERS LIKE KAMLA THOUGH ARE HARD TO FIND*

# We need trained helpers to help caregivers

- There is an urgent unmet need for dedicated, well trained and certified helpers to help caregivers of dementia patients.
- This help may be on daily basis or even once a week basis and would help supplement the care of the dementia patient and give the caregiver a break thus avoiding caregiver burnout.

# NGOs and role of big pharma

- We should explore the role of NGOs and pharmaceutical companies which manufacture drugs used to treat various neurodegenerative disorders in providing ancillary services to support caregivers.
- How do we though make it an economically viable and sustainable endeavor?

# Need for innovative solutions-the Indian Jugaar!

- Every year a substantial number of trained personnel retire from the Army Medical Corps.
- They are relatively young (average age of 38-40 years) and belong to two categories: **Nursing Assistant** and **Ambulance Assistant**.
- At present this talented pool of men largely goes waste. Some are absorbed in private hospitals. Others keep searching for suitable

# An innovative plan that helps everyone

- Retired service personnel get gainful and respectable employment.
- Caregivers of dementia patients get much needed and easy to afford help.
- Over a few years with government and big pharma support the above suggested plan has the potential to grow with the establishment of caregiver aide led Day Care Centers where the caregiver can bring the patient for day care in morning thus avoiding caregiver