

### Long-Term and Palliative Care in India

The concept of palliative care is relatively new to India. In 1975, the Government of India initiated a National Cancer Control Program, which can be termed as the first step towards palliative care in India. Majority of older persons in the age group of (70+ years) in India are in need of long-term and palliative care.

Though providing long-term and palliative care to older persons comes in purview of family responsibilities in India, it is observed that financially independent older persons or older persons with high net-worth or having property entitlements are comparatively treated well by their family members. Majority of older persons with no / inadequate source of income in old age are prone to neglect and their healthcare, financial and social needs & requirements remain unaddressed.

# Salient findings from Agewell Foundation's Study (2018)

- 62.1% elderly respondents don't get any long-term and palliative care in their old age. Only 37.87% older persons admitted that they are getting long-term and palliative care.
- Half of the needy elderly (52.4%) said that they primarily need traditional family support.
- Approx. 29% older persons, deprived from long-term or palliative care, acknowledged that they need maintenance in old age, so that their basic needs can be met and they can lead a comfortable and peaceful life in old age.
- Approx. 13.9% older persons demanded more healthcare facilities and care giving services in old age as long-term care.

# Awareness about the support and services

• Only 28.6% older persons are aware of laws and schemes ensuring maintenance of older persons in India.



• Approx. 71.4% elderly respondents admitted that they have no or very limited knowledge of provisions/schemes meant for them.



#### **Bedridden / Elderly patients**

Among elderly respondents with one or more bedridden/elderly patients

in their respective families,  $1/3^{rd}$  respondents (33.5%) claimed that average period of bedridden status of their bedridden elderly family members is more than 3 years.

- In this category of elderly respondents, 29% elderly respondents admitted that the average period of bedridden status of their bedridden elderly family members is between 1- 3 years.
- Approx. 18% elderly respondents said that average period of bedridden status of their bedridden elderly family members is 6 months to 1 year only.
- Among these family members of bedridden / elderly patients, 11.3% claimed that average period of bedridden status of their bedridden elderly family members is 1-6 months.



- According to 64.12% elderly respondents, loneliness / marginalization / isolation is the most critical issue faced by bedridden / elderly patients as they cannot visit/ meet / interact with their relatives / friends / neighbours, etc.
- 12.58% elderly respondents claimed that lack of proper care is most critical issue faced by older patients and bedridden due to various factors like busy lifestyle of family members, etc.
- 11.45% respondents said that no hygiene / cleanliness is the most critical issue generally faced by older patients and bedridden in their
- opinion.
- When elderly respondents were asked about the best palliative care service for bedridden/elderly patients in their opinion, more than 2/3<sup>rd</sup> respondents (approx. 68%) reportedly agreed that organizing entertainment activities like music, dance, etc. in their houses can be the best palliative care service for bedridden/elderly patients.
- According to 12.45% and 11.88% counseling and interaction activities respectively are the best ways to provide palliative care to bedridden/elderly patients.





# Major challenges being faced by old persons while getting long-term / palliative care

• Most elderly respondents (68.5%) asserted that breaking up of joint family system is one of the biggest major challenges being faced by old people while getting long term care/palliative care.

- More than 2/3<sup>rd</sup> elderly respondents (66.5%) reportedly claimed that fast paced lifestyle of younger family members is the most common challenge for older persons, as it leads to loneliness and isolation in old age, due to which older persons don't get long term and/or palliative care.
- Approx. 60% elderly termed poor financial status in old age as the biggest and a major challenge being faced by older persons while receiving old age care and support services.
- Further, 36.8% elderly respondents opined that loneliness in old age can be recognized as a major challenge, affecting long term and/or palliative care for older persons.



• 1/3<sup>rd</sup> elderly respondents also found services unaffordable for their family members/caregivers, due to which they remained deprived from long term and/or palliative care.

### Conclusion

In India, number of bedridden elderly persons and long-term elderly patients is increasing rapidly. There is an urgent need to initiate some innovative programs and schemes like organizing soothing musical and dance performances, recreational games, and activities for such older persons, who are in constant pain and who have to undergo immense psychological pressures.