HOME CARE
FOR THE ELDERLY IN INDIA

A CALL TO ACTION

HelpAge India | Fighting isolation, poverty, neglect

Ulysses:

Free hearts, free foreheads—you and I are old;
Old age hath yet his honour and his toil;
Death closes all: but something ere the end,
Some work of noble note, may yet be done...
Come, my friends, T is not too late to seek a newer world.
Push off, and sitting well in order smite
The sounding furrows; for my purpose holds
To sail beyond the sunset, and the baths
Of all the western stars, until I die.
It may be that the gulfs will wash us down:
It may be we shall touch the Happy Isles,...
Tho' much is taken, much abides; and tho'
We are not now that strength which in old days
Moved earth and heaven, that which we are, we are;
One equal temper of heroic hearts,
Made weak by time and fate, but strong in will
To strive, to seek, to find, and not to yield.

Alfred, Lord Tennyson

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FOREWORD

India as a country was well known for its strong value of caring for its elders, not out of a sense of compulsion but with a sense of respect and care which the elderly deserve in the sunset years of their lives.

With breakdown in the joint family system and societal values which espoused such concerns and care for the elderly; currently the elderly find themselves totally helpless and hapless with neither the family nor the society taking responsibility for their care. With a current population of 106 Crores, the elderly population is slated to multiply by 3 times in the 60+ age group and 5 times in the 80+ age group in the next 2 decades. This is again made complex by the fact that the dependency ratio is also on the rise (10.9% in 1961 to 14.2% in 2011).

Given the current response of the Government of India, precious little has and is being done in the realm of health and social security for the elderly. Although within the current National Health Mission, the National Programme for Healthcare for the Elderly (NPHCE) has spelt out various care structures and processes for the elderly; the actualisation of the same on ground is inconsistent and far from satisfactory. Given the quantum jump in the elderly population in the coming days, in what is being termed as the "Grey Tsunami", our preparedness as a country is inadequate to say the least.

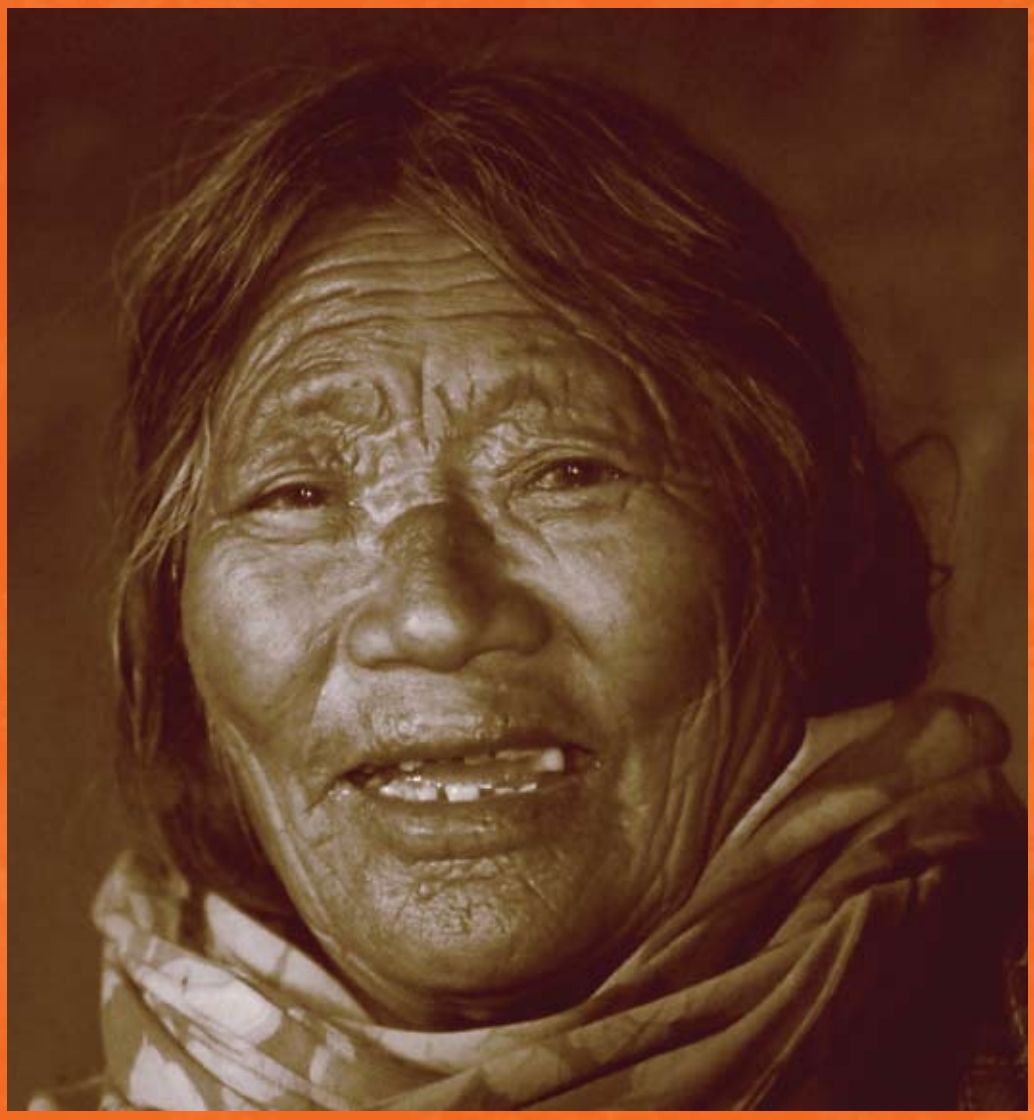
HelpAge India has been working for the last 40 years for the cause and care of the elderly in the country. Given its experience of working with the elderly and understanding their issues; it recognises that the most acute and felt need is that of care for the bed bound, immobile and assisted group who are the most marginalised amongst the elderly. In this regard, it carried out a pilot experiment in 3 locations of the country where home based care was delivered by volunteers which was made possible through community participation and involvement in Shimla (Himachal Pradesh), Leh (J&K) and Cuddalore (Tamilndadu).

Cultural expectations in India are that elderly care be provided at home or in village community are very pronounced and the "Shravan Kumar" model of care of parents is the common theme evoked. However the truth is very different. Our work in the pilot project has indicated that there is a pressing need to find smart policy solutions.

The report is a clarion call for the government to wake up to the issues of the elderly in the country especially of the bed bound, immobile and assisted elderly and how they can respond effectively to the need which is the elderly's basic human and fundamental right as provided by the Indian constitution.

Mathew Cherian
Chief Executive Officer
HelpAge India

I. THE LAST, LOST & FORGOTTEN PEOPLE OF INDIA – STATE OF THE ELDERLY AND THEIR CARE IN INDIA



India as a country is on a high growth curve being the seventh-largest economy by nominal GDP, the third-largest by purchasing power parity (PPP), fastest growing service sector, major exporter of IT services, largest automobile industry and one of the fastest growing retail markets globally. [1234]

Despite such high growth and stride as a major global player on all fronts, the fruit of such rich dividend has not trickled down to its most marginalised and neglected segment – namely the elderly.

It is ironical that the Father of the Nation once said "A nation's greatness is measured by how it treats its weakest members." Hardly would he have realised, that his own country would be in the forefront of neglect and apathy of its elderly who are its weakest members. Elderly form approximately 8-9% of the total population i.e. 106 million (10 crores plus) across the nation making India the second largest global population of elderly citizens. Most of the elderly in the country live a life of destitution, ill health, neglect and abuse which is in direct violation of their basic human and fundamental rights as provided by the Indian Constitution.

In the next couple of decades, the elderly population is slated to increase manifold (persons aged 60+ will increase by 354% and 80+ will increase by 500%)[5] which will surpass the population of children below 14 years[6] as compared to the overall Indian population which will increase only by 40%.[7] The problem of the elderly takes on bewildering proportion with majority of them belonging to marginalised sections - 71% living in rural area, majority being women, widow and nearly half belonging to poor Socio - Economic Status (SES).

> With the rise in the number of elderly to manifold, the country is on the verge of experiencing a tectonic shift demographically in what is popularly coming to be known as the "Grey Tsunami". Such "Grey Tsunami" will result in the country witnessing a sudden and vast rise in the elderly population in the next 2 decades with a corresponding rise in their needs and the total unpreparedness of the country to address them.

With majority of the elderly belonging to the unorganised sector with no formal social security mechanism and health benefits; it is unfair that India's elderly are looking at a life of destitution, ill health and low quality in the sunset years of their lives after having contributed so much to the country in their productive years. As an equitable and just society, how we treat and deal with the problems of the elderly, will be a true pointer to how truly advanced we as a country are on the global platform. Ironically, the emphasis of India's policies also discriminate against the elderly be it indigent persons, widows and also patients needing home care. This may be arising from the point of view of prioritisation as the old are seen as unproductive and spent force no longer useful to a country or its economy as compared to youth or children.

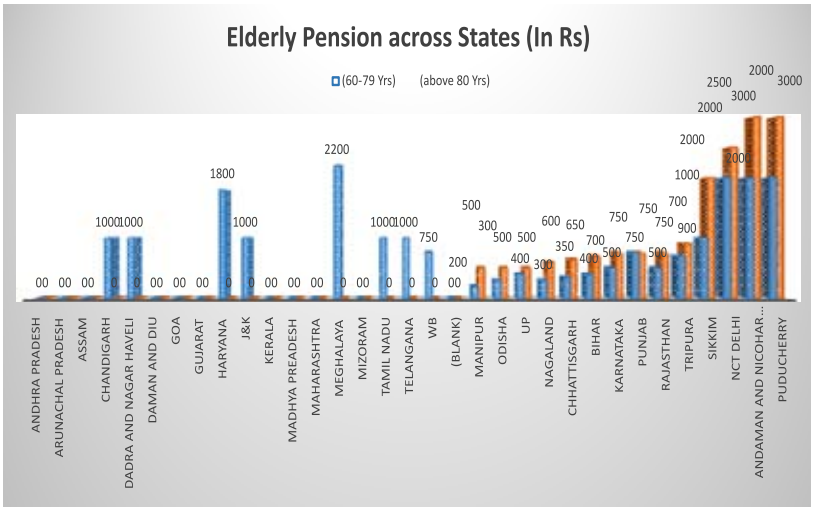
Ageing involves a number of biological changes which affect the Activities of Daily Living (ADL) e.g. reduction in eyesight, hearing and mobility reducing an individual's abilities to sustain independent living for which they need other people's assistance. With the crumbling of traditional joint family system, formation of nuclear families & mass migration of the younger

generation in search of job opportunity; there is a rapidly diminishing support structure for the elderly. With rise in the old age dependency ratio from 10.9% in 1961 to 14.2% in 2011; the elderly increasingly require support and care in their day to day activities. The WHO estimates that there are 500 persons in every district who are terminally ill needing home palliative care. Besides, a rise in the Non Communicable Diseases (Diabetes, Hypertension, Heart diseases and cancer) in the country, majority of which affects the elderly, deepens the crisis for this age group as support structure both in the private and public domain is non-existent for them.

A detailed overview of the government support that the elderly received in the realm of basic amenities like pension, shelter and geriatric care and medical facilities across our various states in the country revealed the following:[8]

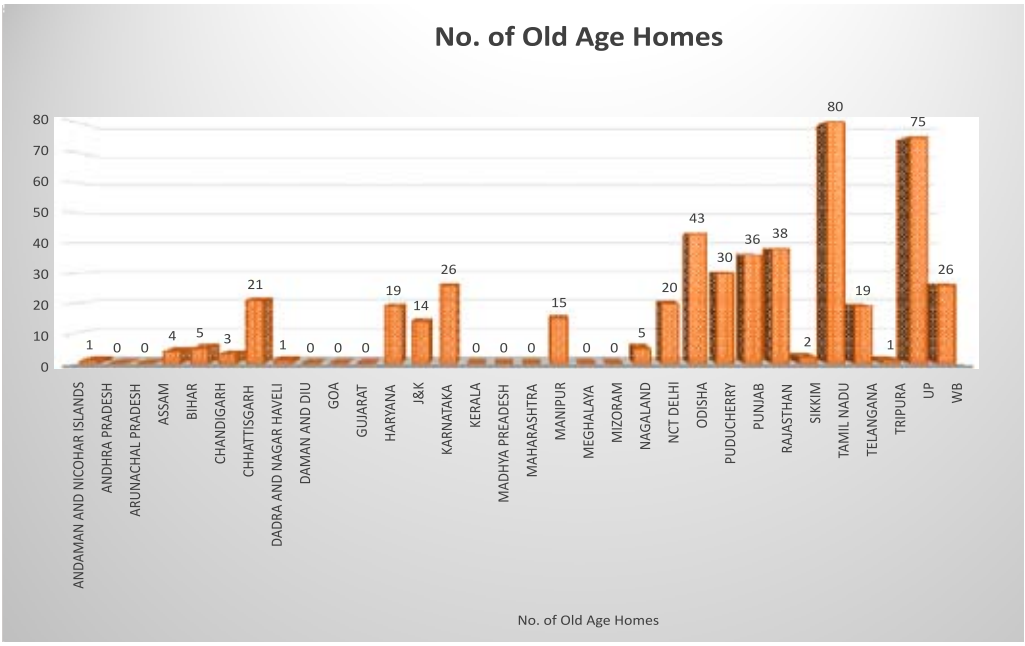
1. Pension for the Elderly:

With regards to the pensions given to the elderly, the data revealed that nearly 10 states did not give any pension in the 60 – 79 years category and 18 states in the above 80 years category. The average pension amount in the 60 – 79 years category was Rs 660.93 (high of Rs 2200 and low of Rs 200) and in the above 80 years category it was Rs 534.37 (high of Rs 3000 and low of Rs 500). The irony of the fact remains that even the highest pension (in both the elderly age category) is lower than the minimum wage.[9]



2. Shelter for the Elderly:

Though there is no organised data on the level of destitution, going by the current overall population data on destitution of 28.5%[10]; India has close to 3 Million elderly who are destitute by conservative estimates. Conservative, as 93% of the elderly in India belong to the unorganised sector and do not have any post-retirement benefits and most of the time are turned away from their homes by children as they are no longer productive. Understanding the burgeoning need of the elderly to a basic shelter, Section 19 of the Maintenance and



Welfare of Parents' and Senior Citizens' Act, 2007 (MWPSCA); prescribes state government to establish at least one old age home in each district with a minimum of one hundred and fifty senior citizens who are indigent. In the affidavit submitted by the state & union territories to the writ petition, none of the states have at least 1 old age home per district and wherever they are, they don't have a stipulated capacity of 150 as envisaged in Section 19 of the Act.

3. Geriatric care and medical facilities for Elderly:

Of the 30 affidavits filed for specific information regarding the number of beds which have been reserved for geriatric care in government or private hospitals and information regarding geriatric centres; 12 states have less than 10 beds per district for geriatric care. Only 6 states/ UT have 10 beds per district. The rest 12 states did not provide any information. Most states & UT (24) do not have geriatric centres in each district and do not have adequate earmarked beds (at least 10 per district as per National Programme for the Healthcare of the Elderly – NPHCE).

The data overall reveals that there is an acute shortage of infrastructure and manpower dedicated for the elderly across the states and there is very little or no focus of the state government on implementation and operationalization of various policies for the elderly (National Policy for Older People, Old Age Pension etc.)

From a public health perspective, we are a country caught up with the unfinished agenda of communicable diseases and maternity & child Health and are staring ahead at the looming challenges of the non-communicable diseases and elderly health problems. There has been a significant improvement in the public healthcare delivery system through the National Health Mission and other initiatives of the government, resulting in significant dents to sensitive indices like maternal, infant and child mortality along with reduction of the communicable diseases. However, the fact again remains that from a public health delivery point of view we are still severely challenged to deliver need based basic care due to emerging infrastructural and manpower issues. National Health Policy, 2017 also aims at "Universal Health Coverage

and affordable quality health care services for all". While the National Health Policy, through the National Programme for Healthcare of Elderly (NPHCE) attempts to address the health issues of elderly; on ground implementation and execution leaves a lot to be desired.

Given the increasing destitution with little access to basic support like pension, shelter and healthcare; the elderly are increasingly on a path of helplessness and dependency.

As per the report of 71st Round in National Sample Survey Organisation (NSSO), 8.4% of elderly in the rural areas and 7% elderly in urban areas are physically immobile. It also brought out from the report that 34% of elderly in the rural areas and 27% of elderly in urban areas are confined to their homes owing mostly due to immobility & health issues due to increased dependency rate especially as the proportion of "old – old" (above 80 years) increases in the country.

The physically immobile and those confined to home due to increased dependency rate, are the most marginalised amongst the elderly in our country. Assuming that the public health system does gear up to serve the need of the elderly in the country in the coming days, this group will again be the one who would mostly miss out due to the last mile challenge of access owing to immobility and confinement at home. Such elderly group will not be the only group which will be deprived of the fruits of development but also the large group of family members/carers who will miss out on productive vocation as their time will be spent on looking out/caring for this group of elderly.

As per a study by the UN, 62.1% of elderly in India do not get Long Term and Palliative Care and managing home care for the elderly is a massive challenge as multiple service providers—nursing agencies, physiotherapists and medical suppliers—are small scale and unorganized and, therefore, provide incomplete care.

Such large group (immobile elderly & their family members/carers) will translate into a huge loss in overall productivity to the tune of US $ 18.75 Billion per annum to country's economy.[12]

II. HOMECARE PILOT IN 3 STATES - AN INNOVATIVE COMMUNITY LED EXPERIMENT FOR CARE OF THE ELDERLY

The lack of health care for the elderly will not only be a loss to the country's economy but cause increasing burden and strain on the public health infrastructure and manpower in the country in the coming days. In order to arrive at a model of care provision which is effective (cost & program wise), community – led, can be taken up within the existing public health system initiative (NPHCE) without much additional budget commitment and is sustainable in the long run; HelpAge India carried out an innovative pilot with community participation in 3 locations across the country – Shimla (Himachal Pradesh), Leh (Jammu & Kashmir) and Cuddalore (Tamil Nadu).

In countries of Southeast Asia like Thailand, there is a national strategy and policy for Long Term care for the elderly. The tax-financed community-based long-term care program of Thailand was piloted from 2016 and aims to provide support to informal carers through care giving and case management support. Trained caregivers provide 2-8 hours of home visits a month to bedridden older people, managed by case managers. Care services are coordinated with health and social work services. By 2018, the community-based LTC program has trained 44,000 caregivers to provide care to 193,200 older people for a budget of 1.159 billion THB (approx. 36.4 million USD). Local governments (LGs) are responsible in managing the LTC program with the support from ministries (Ministry Of Public Health) and are financed from the universal coverage scheme (UCS) and local government channelled through local health funds (LHF).

Given the promising and successful way in which countries like Thailand have addressed their issues of Long Term Care for the Elderly; the pilot intervention by HelpAge India was an experiment to ascertain if a similar approach can be taken in India and hence carried out the pilot in 3 locations of Shimla (Himachal Pradesh), Leh (Jammu & Kashmir) and Cuddalore (Tamil Nadu). ..

1. Choosing the intervention locations:

The 3 locations were chosen based on prevailing problems of the elderly and remoteness which makes care provision difficult. Himachal Pradesh has 7 lakh persons aged 60 years and above, constituting 10.2% of its total population which is higher than the national population of 8.6% (Census 2011). The total elderly population of Leh is 14,602 which is 11% of the total population. More than 95 % elderly live in the rural areas where medical facilities are very poor apart from the difficult topography & harsh climatic condition. Tamil Nadu has the second highest percentage of senior citizens (above 60 years) in the country with majority living in rural areas having limited access to health care. Also the 3 states lagged behind in the parameters of pension, shelters (with the exception of TN) and Geriatric care and medical facilities (with the exception of TN).

A preliminary baseline study was done across

The intervention took in to account the state of public health and social security mechanism and provision for elderly in the country, which is found to be meagre and insufficient. It concluded that successful long term care for the elderly could only be ensured if the family and the community members together are sensitised to the issue and their capacity built to take care of the elderly at home. This is also reiterated by the fact that most of the elderly in India would prefer "Ageing in Place" to an institutional set up.

these three states to understand the need of elderly especially in terms of support required by them. In the total sample (n=2500), a significant percentage of the elderly (59%) were suffering from a long-term disease that required regular medication. One half of the elderly (53.8%) in the survey reported that they need help from others to carry out their ADL[11] activities. As compared with Shimla and Cuddalore, Leh reported a very high need of Home care services (55.8%). The common health problems among the elderly are incontinence (32.5%), hearing (22.9%) and poor vision (21.1%). In the total sample, it can be seen that an overwhelming percentage of the elderly reported need for support in IADL (97.8%)[12] activities ranging from travel to outside places, difficulty with managing money, difficulty for shopping and difficulty in finding address in unfamiliar places. It is interesting to note that female elderly outnumbered male elderly in reporting need for help (57%). Results of the study clearly indicates that majority of the elderly population living in these three locations requires assistance from others in order to carry out their activities – both ADL & IADL (53.8% & 97.8%). Therefore, it was seen, on the basis of baseline study, that there is a greater need of provision of care at home or home care services in these 3 states.

Given the state wise available data and baseline data from the 3 locations, it was seen that there is a need to intervene with an innovative pilot which demonstrates the provision of care to the elderly at home and also establishes a sustainable approach to such delivery.

Hence the fundamental approach to carrying out such a pilot was based on the premise that community and family member's participation together in the project is a non-negotiable and the only way in making it effective, sustainable and acceptable. The baseline study also revealed that the beneficiaries (bed bound & immobile elderly) preferred family members and someone known to them deliver the care (47%).

2. Project Implementation:

The project followed the following steps in its implementation:

I. Putting elderly at the centre of the project:

At each of the project location, the formal community entry strategy was adopted – explaining the village Sarpanch and members about the project, taking their consent, seeking their inputs and carrying out community sensitisation. The community sensitisation, amongst others, utilised tools like street plays where the issues of the elderly were depicted with special focus on the plight of the bedbound, immobile and assisted elderly. Such community mobilisation yielded motivated volunteers who enrolled to support the project implementation. As seen in most cases at the 3 locations, majority of the volunteers (70.2%) are family caregivers.

The volunteers were trained to identify bedbound, immobile and assisted elderly in their villages. The elderly after being identified were mapped by the volunteers with regards to their need for support after elaborate discussions with the elderly and their family members.

Location	Villages covered	Total beneficiaries covered	Care-givers trained	No. of caregivers trained		No. Of training Program conducted
				M	F	
Shimla	**26**	750	255	119	136	16
Leh	**21**	470	226	96	130	10
Cuddalore	**20**	700	235	70	165	12

ii. Capacity building of the Village Volunteers:

Based on the elderly's care giving needs from the 3 locations, a detailed training curriculum was designed with the support of the school of nursing, All India Institute of Medical Sciences, New Delhi. The curriculum, apart from the soft skills of dealing with the elderly, focussed on teaching basic techniques on moving the elderly, providing them basic support in activities of daily living (brushing, bathing, and toileting), monitoring their health, outdoor activities and linking them to various government schemes/benefits.

Hands-on training of the community volunteers on elderly caregiving

The training was divided in to the Training of Trainers (ToT) and training of volunteers. In the Training of Trainers; the project manager, coordinator and cluster coordinator were trained on the various modules. They in turn further trained the volunteer caregivers. Training was planned in a quarterly manner ranging from basic to complex topics in a chronological order.

iii. Provision of care at Home:

Each volunteer was mapped to 3-4 bedbound/immobile/assisted elderly nearby his / her place of stay. If a volunteer happens to be a family caregiver, then he/she is entrusted to take care of 2 more elderly in his/her area. An elderly specific care giving rooster (based on the elderly's specific needs) was drawn up with the help of the project coordinator, volunteer and family members. The frequency of visit ranged from daily to 2-3 times per week. The caregiver visited the elderly routinely and provided various care to them at their homes. Such care provision and close follow up ensured that the elderly actually regained their functional ability and are able to carry out their daily activities on their own.

What is age but just a number...

Mrs Krishna Devi looked up at the setting sun behind the mighty Himalayas hoping to see one of her sons coming back from the city to visit her. All of 86 years, she lives alone as her two sons are away to earn livelihood in the cities. She looked around to see the lush green crop which swayed on the mountain steppe symbolising prosperity, happiness and abundance all around. Being a well to do cash cropper, the family never felt it necessary to invest on children's education. However, bad time fell on them due to the sudden illness of her husband due to which they had to sell off their lands. As a result of this her sons were left without any education or land to tilt. Her sons, despite working hard, were not able to make good money to run the house and take care of her forcing them to move to the city in search of work. In the course of time, they have married and settled in the city and only visit her occasionally.

Mrs Krishna Devi has multiple mobility issue due to arthritis and about a couple of years ago was diagnosed with a heart ailment. Despite her need for support and assistance, she never deems it appropriate to call her sons as she believes that by doing so her sons' livelihood will be affected. Like any other benevolent Indian mother, she suffers her agony silently taking the help of friends and neighbour while murmuring prayers of blessings for his sons to flourish in their livelihood.

Mrs. Lata Kaushal, a neighbour and sympathetic human being, used to look after Mrs Krishna Devi but often time found herself inadequate for the challenge as most of the caregiving activities were tasking and exhausting even for an able bodied person like her.

(Beneficiary Mrs Krishna Devi along with home caregiver during a visit to PHC)

At this point of time, Mrs Kaushal came to know about the Homecare Pilot project initiated by HelpAge India in Shimla and found it a godsend for her! She was one of the star volunteer who asked lots of questions and took keen interest in the training programme. "Whereas the project team thought it their good fortune to have a dedicated volunteer like me, I was thanking the almighty for initiating a project like this in our locality which was such a heaven sent gift for me as it not only told me techniques of caregiving but also made my work easier and effortless! Learningfrom the experts from AIIMS and HelpAge India made it doubly fulfilling!"

She also learnt on developing linkages with government services and schemes and as such accompanies Mrs. Krishna Devi to the local PHC for her monthly check-ups. Over a period of time she was able to bring Mrs Krishna Devi from her house in to the community and facilitated her interaction.

With right attention, care and treatment along with socialisation; Mrs Krishna Devi is now a rejuvenated person. Brimming with joy a confidence she says:

"Lata's support and care has shown me all that is good in the world for which I will always be eternally grateful to her. May god bless her for saving me and showing me that the world is still beautiful and full of hope"

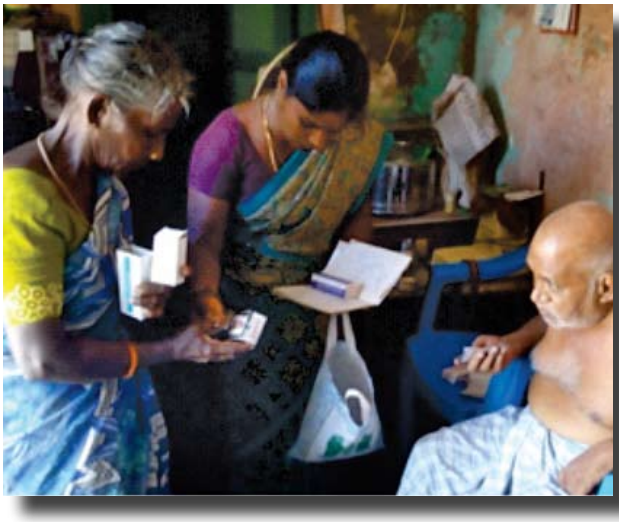
As she prepared herself to go and attend a nearby marriage in the evening, we half-jokingly asked her if she is not afraid to go in the dark at this age to which she winked and said " what is age but just a number"…

A Ray of Hope:

Mr. Krishnan was a blessed man with a loving family consisting of a wife, two daughters and a son. The couple worked together in their own business, where they used to sell garments door to door. Life took an unusual turn for the worst when Mr Krishnan suffered a stroke and was affected by paralysis. After then, the journey was an uphill task without the support of their chief bread winner. From earning enough to provide for two square meals per day, the family now had the huge burden of managing the medicinal expenses of Mr. Krishnan too. A happy family was turned in to a hapless one due to the unfortunate turn of event.

Pushed in to desperation, two of his son and daughter migrated to Chennai for odd jobs. The eldest daughter is married at Chennai and managing her own household. Now Mr. Krishnan's wife is the sole breadwinner of the family working as a mason in the locality. The earnings of being a Mason is just enough to meet their food needs and most of the time the couple struggle to get medication for Mr Krishnan. If that was not enough, most of the times his wife is unable to leave him alone and has to forego any gainful work that may come her way in absence of anyone to look after him.

Mr. Krishnan's health condition deeply affected the financial and social status of the family. He was slowly becoming a burden on the family thereby losing his confidence and was surrounded by negative feelings of being worthless, isolated and neglected which eventually pushed him towards depression. He used to be a very active person in the society and was a member of the local societal associations but now has restricted himself to his home. Being



(Medicine support provided by our volunteers)

(Treating the wounds by our trained volunteers)

dependent on others for carrying basic daily activities, when his wife is gone, makes him feel ashamed and helpless. From an active and productive person, the feeling that he has become a burden on everyone sums up his sufferings. When all seemed lost and gone in Mr Krishnan's life, a ray of hope came in the form of our Home Care Volunteer G. Manikkavali for the family. She identified Mr.Krishnan as a Home Care beneficiary and identified his specific needs. She was trained by the HelpAge Homecare and AIIMS Nursing Team on how she can take better care of Mr Krishnan. She not only took good care of Mr Krishnan but also freed the time for her wife to earn livelihood.

There has been a sea change in the life of the beneficiary as well as the family. Our trained community based geriatric caregiver apart from the basic support to carry out day to day activities, has given psychological support by personally visiting him, helping him gain confidence and assuring that he is also an integral part of the society. Apart from psychological support, he's been given equal attention on the part of physical assistance. This includes bed making and exercise for his ailment. Also he is being monitored with blood pressure and other vital parameters to ensure constant stability in his health factors. The home care team is also taking initiative to provide basic physiotherapy exercise to improve the condition of his immobility/dysfunction.

The smiling face all around shows that the family is happy that somebody is taking care of Mr Krishnan so that his wife can earn a livelihood and also of our volunteer G. Manikkavali who is happy to have been of some service to the needy family with the spirit of care and service

Thu-chi che HelpAge India:

Ktavao looked at his daughter nostalgically as she cuts his nail and prepares to clean him like an expert. It just seems yesterday when little Stanzing came in to his hand as a gift from the Mahabodhi himself. Ktavo was like any other average grim (barley) farmer and had a beautiful wife. Unfortunately his wife died due to illness before they could have any children. Ktavao then immersed himself in work forgetting everything else. As he lived his life alone

people urged him to marry again. Somehow, he could not bring himself to that. Instead he came to hear about an orphanage in the city and that is where he first met Stanzing whom he held for the first time in his hand.

Few years ago, when he was working on his mountain field of his, he lost balance and fell. While the fall was not too steep, his right leg got injured quite badly. Inadequate attention and lack of immediate medical treatment, did not help the matter either. As a result of which his mobility got reduced and he could hardly move about carrying out his activity of daily living. With increasing age, his other faculty also failed him and he became slowly dependent on others

Stanzing came to his rescue in this hour of crisis. From the loving daughter, she took up the role of a strict mother. From helping him to walk to feeding him and cleaning him up became part of her entire universe.

However, Ktavo slowly noted that Stanzing did not have much of a social life of her own. Her entire universe rotated around him and his need and there was very little time that was left for her. Though they did not have much of financial crunch as he has saved enough, seeing her daughter socially isolated made his heart bleed.

At this point in time, Stanzing heard about the Homecare Project in Leh by HelpAge India. She went and enrolled as a volunteer. Hearing about her problem, the project team identified another volunteer (Rabzas Lamho) to help her in the caregiving while Stanzing pursue some skill building training to keep her engaged and also earn.

It has been a year since the project has started. Both Stanzing and Rabzas have been trained on the techniques of elderly caregiving. Due to the volunteering of Rabzas, Stanzin has now got the opportunity to work as tour guide with a local tour company. Apart from earning her a livelihood, it has been able to cheer her up. Each time Ktavo sees a cheer in her daughter's face, his own eye lit up and he could only say "Thu-chi che HelpAge India" ("Thank you" HelpAge India in Laddakhi)

A caring daughter lends a helping hand to her ailing elderly father

iv. Establishing Linkages (Intra & Inter):

One of the main aims of the project was also to see how linkages could be developed for the benefit of the poor. Before the project looked at developing inter linkages, it had to ensure that it linked the elderly to the various programs of HelpAge India namely the Mobile Health Unit (MHU), Physiotherapy services and Helpline. By ensuring the intra linkages, it was seen that the elderly benefitted from the visit of the MHU and physiotherapist through referrals by the volunteers. The elderly and family also utilised the 24x7 Elderly Helpline of HelpAge India to avail benefits from its various projects and also gain insight on various schemes/ programmes of the government.

The project, through its volunteers, ensured that the elderly are linked to various schemes and programmes of the government. One of the critical factor to receive the benefits of government scheme is the Aadhar card which is the Universal Identification system in the country through which the beneficiary are linked to various schemes. At the beginning of the program many beneficiaries did not have Aadhar cards. The project ensured that the cards were made through facilitation with the local Aadhar units. On an average, 54.8% elderly were linked to the pension, Antodaya scheme (Public Distribution System for food grains), health insurance and other such beneficial schemes (HelpAge Advantage Card. & physiotherapy).

Linkages with HelpAge Mobile Healthcare Unit at 11500ft above sea level

Through the project, the elderly were also linked to the local got. health centre where the public health staffs including the doctor's awareness about elderly issues was raised. The referral and treatment of the elderly were facilitated by the project and the referral chain built up to secondary and tertiary hospitals. In certain locations (Shimla & Cuddalore) the local government hospitals (Indira Gandhi Medical College, Shimla and Jawaharlal Institute of Post Graduate Medical Education & Research in Pondicherry for Cuddalore) linkages were developed whereby they not only provided treatment & hospitalisation care but also actively got involved in training and awareness activity with the project team.

v. Working with the government system:

The project, through its various initiatives, also established successful linkages and partnerships with the local governance structure. District level government functionaries including the collector were involved in the various training and awareness building programme. For example, Mission Director, National Health Mission in Shimla felicitated community caregivers during training program, District level In charge for national health mission supported home care project in Cuddalore. Additional deputy commissioner in Leh attended Home care training program. In most of the places we got very active support from the local authority at the panchayat, block, district and state level. In Shimla

The project, in its 2nd year has demonstrated that a community led, volunteer run elderly homecare initiative can be a success given that we are able to work with the community, ensure high quality training to the volunteers, develop linkages and ensure everyone comes together for the welfare of the elderly. Intact the project has been an eye opener for HelpAge India as total strangers in the community came together to cater to its elders in the most compassionate and empathetic manner possible.

Rural the Panchayat Pradhan himself became an active care provider to the home care beneficiaries and helped in generating awareness in the community, Chief Representative Officer of Tibetan refugee camp sensitised the community about home care services, Resident welfare associations in Shimla facilitated in the training programs. Such collaborations and linkages helped us to explain the need for Homecare for the elderly to the local government representatives thereby getting their support and support of the associated structure like health centres, Aadhar enrolment centre, linking elderly to government programs & schemes.

Of the various needs of the elderly, the most acute and critical is the need of its bedbound, immobile and assisted elderly who will always be marginalised due to their lack of mobility resulting in issues of access to various services & programmes.
While health systems wake up to the unique need of this group of elderly and the private sector understands the demand for trained manpower; it is imperative to explore the community & family caregivers' model where these two stakeholders are trained and their capacity built to take care of the needs of this group of elderly.

vi. Impact:

After the implementation of Home Care Pilot Project, there has been a great change in the life of beneficiary as well as the family. As an immediate result, the beneficiary needs has been addressed for the issues of bed sores and helping with daily activities. Our home care volunteer together with the family started ensuring hygiene and safety of the beneficiaries. With trained assistance in handling bedridden elderly, it has reduced the burden of the family in taking care of her. Because of this, the support from local community has also increased for our project and its staffs. With continuous support from our trained home caregiver and visits by physiotherapists efforts were made to give the beneficiary confidence in regaining functional ability again. Through the project, the beneficiary were mainstreamed again by encouraging and facilitating socialisation. In the long run beneficiary feels that the community would support them to lead a dignified and safe life irrespective of their socio-economic status. This creates a positive environment not only for the elderly people at present, but also for the future elders.

With the support of our caregiver volunteers, family which earlier were not able to work for livelihood are now freed to pursue vocation which is financially fulfilling. Thus such support has resulted in providing the family breathing space and a break from the "Caregivers' Stress".

Linkages with government schemes and services has empowered the elderly in getting the benefits which was right fully theirs. Linking with health systems like PHC and district hospitals are helping the elderly get free healthcare and also helps in sensitising the health staff on the unique needs of the elderly. It also helps the staff in sensitising the elderly in self-care and preventive/promotive health and the role that care givers can play, which takes much of the burden out of the public health system.

III. CARE FOR THE ELDERLY - WAY FORWARD

While the monetary cost (real & opportunity cost) of not providing care for the elderly was estimated to be US $ 18.75 Billion per annum; the societal value/cost will be sizeably high and damage irreparable in the long run. As a progressive country which strongly believes in human rights and is committed to providing the highest quality of life for its citizen; the elderly in the country today has a different story to tell. The elderly in our country are not only the most neglected, abused and marginalised; but also are a large group who are denied basic fundamental human rights due to the absence of positive policies by the government catering to their need.

Based on our experience of Homecare for the elderly in the 3 locations through a community and family led model; it is possible to address the issues of the bed bound, immobile and assisted elderly at a country level with slight tweaking and operationalization of many components of National Programme for Healthcare of Elderly (NPHCE) as described below:

i. At the Sub Centre/Village Level:

a. An elderly caregiver (can be named as Vridh Sahayak) can be trained on provision of care for the elderly apart from identifying health issues of other elderly and referring them.

b. The Vridh Sahayak will map the cluster of village under a sub centre for elderly in the family and find out bedbound, immobile and assisted elderly.

c. S/he will identify community volunteers/family caregivers who can be trained to provide care to the elderly on a regular basis after proper mapping of their needs and drawing up a caregiving roster through which the Vridh Sahayak will monitor the work of the community volunteers/family caregivers.

d. The Vridh Sahayak will be responsible for the elderly health in all the villages under a sub centre starting from preventive, curative and rehabilitative care.

e. The Vridh Sahayak will be linked to the ASHA Workers who could then support them to monitor and carry out care giving at a village level.

f. They will ensure that assistive devices (calliper, walking sticks, knee braces etc.) are provided to the elderly to make them ambulatory.

g. Ensure annual check-up by the PHC/CHC including non communicable diseases.

ii. At the Primary / Mandal Level:

a. Ensuring the referral of the elderly to primary health centre is given attention for which sensitisation and training of the public health team (including the doctor) will be done as per the provision laid down in the NPHCE.

b. Weekly once geriatric clinic needs to be initiated at the PHC with proper management of NCD's with availability of medications.

c. Posting of one qualified physiotherapist needs to be made to address the physiotherapy need of the elderly especially bedbound or immobile elderly suffering from paralysis or age related immobility with an effort to restore functional ability.

d. Each Vridh Sahayak from each of the cluster of villages will ensure linkages of the elderly, especially immobile elderly, to various schemes and programmes of the government meant for their welfare.

iii. At the Secondary / District Level:

a. Ensure that the geriatric clinic and ward is set up as per the recommendation of NPHCE.

b. The Vridh Sahayak will closely follow up with the primary as well as secondary centre/ hospital to ensure that all the elderly that were referred have been given the required intervention and treatment as per need.

c. Each district level hospital should have provision for 25 beds in their in-patient ward for elderly requiring long term care.

d. It will be a hub for sensitisation, training and capacity building of all public health team at a district level on geriatric health issues and their intervention.

e. As the implementation of the NPHCE is constituted under the state/district NCD cells; the program assistant of the District NCD Cell can be given the direct responsibility of monitoring the activity of NPHCE especially Homecare in the district. The overall monitoring and supervision of the program assistant can be done by the District NCD officer and Programme Officer.

f. The training will be provided by nodal agency (Reginal Resource and Training Centre) which in turn can be trained by agency like HelpAge India in collaboration with tertiary care institute like AIIMS.

iv. At the Tertiary / State Level:

a. The state NCD Cell Team would need to monitor the progress of the elderly care giving initiatives under NPHCE through a specially appointed State Geriatric Care Program Manager who will manage the project with the support of the District Medical officer and District NCD Cell.

b. Regular monitoring and reporting format would need to be instituted to get a weekly, monthly, quarterly view.

c. Monthly review can be done by the PHC medical officer along with the Vridh Sahayaks of all sub centre under the PHC's.

d. A quarterly review meeting can be done by the district programme officer – NCD Cell with all PHC medical officers along with the Vridh Sahayaks under the district.

e. The State Geriatric Care Program Manager can join remotely through video conferencing and should make it a point to visit each district at least once/twice a year (depending on the number of districts) for such meeting in person.

v. Elderly Care giving as an opportunity for youth skilling

There is a growing Caregiver crisis in India especially in the urban area. The demand for Caregivers far outstrips the current supply brought about by the crumbling traditional joint family system, formation of nuclear families & mass migration of the younger generation in search of job opportunity. The care giving support for the elderly has become sparse and non-existent. Further, there is a lack of trained & qualified Caregivers who have undergone training under a standardized care giving curriculum. Need for skilled, allied & healthcare professionals such as Caregivers to the tune of 7 lakhs over 2013-22 has been envisaged in reports by Health Skills Gap analysis Reports and NSDC. With over 30% of youth aged 15-29 in India not in employment, education & training[13], the Caregiver role becomes a right vocation – to train and pursue.

Given the opportunity, the government can set up skill training centres which train the youth on elderly care giving and sets them up for employment.

IV. CONCLUSION

Given that India as a country is a leader in economic, scientific and technological arena on the global platform; the way it treats its most marginalised segment namely the elderly leaves a lot to be desired. The elderly in the country, most of whom are from the unorganised sector, do not have any social or health safety nets which cater to their basic existence needs in the sunset years of their lives. Being no longer productive and shunned by the society and government who no longer feel accountable; they are driven to despair, destitution and in most of the cases are forced to beg.

Given a society which is founded on the collective ethos of justice, equality and restoration of basic human rights to its entire citizen and guaranteeing them a life of dignity; India needs to wake up to the silent sufferings of its elderly. Amongst the elderly, the most marginalised and neglected are the bedbound, immobile and assisted elderly with an unmet need for Long Term and Palliative Care (62.1%). Given that the proportion of elderly and especially those above 80 years is going to increase exponentially in the next few years; our public health facility & institutions are not ready to take on the challenges of the Long Term and Palliative Care needs of the elderly.

Realising the imminence of such a "Grey Tsunami" and understanding the impact such Long Term and Palliative Care need is going to have on our Health system and the country; HelpAge India carried out an innovative pilot in 3 locations of India (Shimla, Leh and Cuddalore) to experiment on the concept of Community and Family Caregivers for Long Term and Palliative Care need of the elderly. Such a concept has already been successfully tried in many Southeast Asian countries like Thailand.

The pilot trained and built the capacity of family members, neighbours & community caregivers on various aspects of elderly care giving which meets their Long Term and Palliative Care needs. The pilot also focussed on how the elderly could be mainstreamed through linkages with government schemes, programmes and health facilities. The focus was to not only provide support to such elderly but also ensure through support & linkages their functional ability is restored and they are able to take care of themselves and live a life of dignity.

The experience from the project is encouraging and eye opening at the same time. It is seen that with the right kind of community mobilisation and participation, it is possible to ensure that the community and family members come together in ensuring care and health for their elders in the true spirit of respect & caring for their elders which has been a bedrock of India's societal value. The project also brought to fore the fact that such involvement and participation of the community, in a large way, helps in mainstreaming of the elderly in a holistic way (mental, physical and social). The project also demonstrated that the government health systems also respond better when they are explained about the purpose of the intervention and it is possible to build their capacity and skills to take care of the Long Term and Palliative Care need of the elderly in the community.

The experience from the project, our understanding of the enormity of the elderly issue in the country and the adverse impact it will have if things go unaddressed; culminates in a simple but powerful set of recommendations (as delivered in the previous section) which are effective (cost & program wise), can be taken up within the current public health system initiative (NPHCE) without much additional budget commitment and which is sustainable in the long run.

Such an approach postulates the strengthening and capacity building of the community and family members as the primary care giver for elderly requiring the Long Term and Palliative Care. With slight tweaking in the current NPHCE (Vridh Sahayakat sub centre, physiotherapist at PHC and State level Geriatric Programme Manager) and ensuring its proper delivery. This will result in a comprehensive system of care which can be instituted without much investment which inflates public health expenditure and suggests major change in the existing policy.

Such a policy change would benefit many numbers of bedridden/assisted elders who would be provided with home care services by the community & family members leading to a society which is sensitive and caring to its elderly. This will lead to creation of "Elderly Friendly Communities" in which we hope our pilot project had a small role to play thereby contributing to the vision of building a better future for our elderly people.

[1]"World Economic Outlook October 2018: Report for Selected Countries and Subjects". International Monetary Fund (IMF)

[2] PPP (current international $)", World Development Indicators database, World Bank. Database updated on 1 July 2017

[3] Data refer to the year 2016. [1] (selecting all countries, GDP per capita (current US$), World Bank).

[4] "Moody's upgrades India's government bond rating to Baa2 from Baa3; changes outlook to stable from positive". Moody's. 30 November 2017.

[5] Raju, S. (2006). Ageing in India in the 21st Century: A Research Agenda. Mumbai: The Harmony Initiative. Available: http://harmonyindia.org/hdownloads/Monograph_FINAL.pdf.

[6] Raju, S. (2006). Ageing in India in the 21st Century: A Research Agenda. Mumbai: The Harmony Initiative. Available: http://harmonyindia.org/hdownloads/Monograph_FINAL.pdf.

[7] Census of India - 2011, SRS -2013 & Elderly In India Report –2016 , Ministry of Statistics and Programme Implementation, GoI

[8] Response to writ petition (civil no 193 of 2016) vide Annexure P/4by Shri Ashwin Kumar to Supreme Court of India by various states.

[9] https://clc.gov.in/clc/node/586 From the Chief Labour Commission Website on VDA Minimum Wages order dated 28/9/2018. Retrieved on 11/02/2019

[10] Alkire, S., Chatterjee, M., Conconi, A., Seth, S., and Vaz, A. (2014): 'Destitution: Who and where are the poorest of the poor?' Oxford Poverty and Human Development Initiative, University of Oxford.

[11] The things we normally do in daily living including any daily activity we perform for self-care such as feeding ourselves, bathing, dressing, grooming, work, homemaking, and leisure

[12] IADL – Instrumental Activity of Daily Living. Support required to carry out specialised activity to do with using instrument/skills to carry out day to day activities related to independent living

[13] OECD Economic Survey: India 2017

"It is not sufficient to add years to life but the more important objective is to add life to years"

HelpAge India | Fighting isolation, poverty, neglect

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