

Dementia India Strategy Report



Prepared By:

Alzheimer's and Related Disorders
Society of India - 2018

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Vision

Ensure comprehensive sustainable dementia diagnosis, care, rehabilitation and supportive services across the country

Mission

The mission is to make dementia a national health priority and increase resources to strengthen risk reduction, early detection and supportive services, advance research, capacity building and policy promotion for dementia. Government could be guarantor and enabler to better dementia services by engaging all relevant support institutions.

Background

India is witnessing improved life expectancy, which necessitates graceful ageing as one of the important growing public health challenges. Consequently, India is rapidly seeing a surge in number of people affected on old age related problems such as Alzheimer's and related disorders, including rise in cases of young early onset of dementia. An estimated 4.4 million people are living with dementia as of 2015. This number is projected to double by 2030 to 7.6 million and 14.3 million by 2050 with a huge cost to the community and to the government. Further, it has been estimated that the dementia care services will soar to 0.5% of GDP.

The elderly population comprises of 8.9 % (110 million) of the total population and a majority of them are vulnerable for dementia and other chronic conditions. A significant proportion of the elderly population is bedridden. Therefore, there is a need for India specific, culturally acceptable, cost-effective approaches to address Alzheimer's and related disorders. The national strategy document is to facilitate setting up of dementia friendly community centres that allow synergy of family and community support system with appropriate continuity of medical care services at all levels. Strengthening preventive measures, risk reduction early detection, access to best medical care and improving social support services which includes dementia care skills research and information management related to dementia would be important overarching objective of this strategic document.

What is in the National dementia strategy plan?

The National Dementia Strategy plan is an initial step to bring transformation in ensuring comprehensive dementia services. This outlines the government's plan to commit resources that are necessary to address the problems of dementia. There are seven core areas to set out as national priorities in the national strategy. Across seven areas, there are key targets and priority actionable issues which are all linked to certain values and guiding principles.

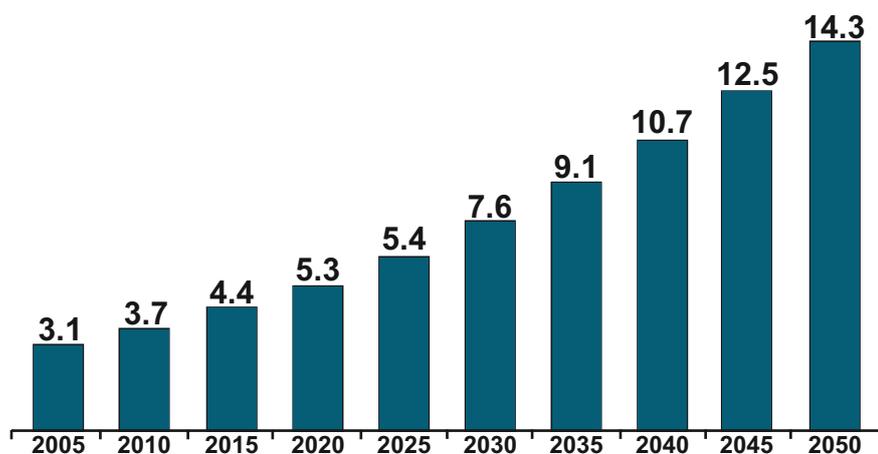
Why the National Dementia strategy

The Dementia India strategic plan is in response to the growing number of people affected with dementia at the state and national levels. This document provides clear direction to meet the needs of those currently affected as well as people who will live with dementia in the future besides offering services to provide for timely diagnosis and early intervention.

There is a minimal attempt to address various issues related to dementia, despite having multi-dimensional challenges. This is presently not a priority healthcare issue in India and is therefore, under-funded. It has been observed from experiences of a range of organizations working in the field of Alzheimer's and related disorders that people affected by dementia and their families often feel desperate and frustrated with challenges they face in terms of healthcare facilities or social needs. Thus, this national strategic plan is expected to receive a commitment from the government on yearly basis for funding, capacity building and research to transform the dementia care and support services at State and National levels.

Dementia – Steep increase in numbers

Number of People with Dementia in India (in millions) (Source: ARDSI 2018)



over 4.4 million people with demwntia in 2015
Number expected to double by 2030
Only 10% of cases are diagnosed

Dementia services gap

Dementia services in India are scarce and limited. The Alzheimer's and Related Disorders Society of India (ARDSI) established in 1992 has spearheaded dementia advocacy through its 20 chapters across the country. There are few more organizations offering dementia care services either independently or with the support from ARDSI.

The services being offered exclusively for people with dementia are:

- a) Day care centres-15
- b) Residential care facilities-12
- c) Domiciliary care services-6
- d) Memory clinics-100
- e) Dementia help lines-10.

There is a significant inadequacy in establishing and running the dementia care centres in India when compared to the proportion of number of dementia cases.

The 7 Actionable Areas

(Inspired from the WHO global Dementia action plan)

Sl.No	Actionable areas
1.	Make dementia a national health and social care priority Declare dementia as one of the national public health priorities
2.	Dementia Awareness and dementia friendly communities: Develop comprehensive sustainable awareness information packages to address multi-stakeholders including service providers
3.	Risk reduction and dementia prevention Reduction of Non communicable diseases (NCD), alcohol consumption, salt intake, hypertension, tobacco, indoor air pollution, Increase Physical activity, availability & affordability of NCD drugs.
4.	Improve access to best medical care, strengthen standard treatment protocols. Strengthen and augment tertiary care regional centres for elderly/dementia care, develop patient centric care plan and continuity of care plan.
5.	Social support services: Inclusion into health insurance, standard civil dispute settlements, create dementia friendly environment in transport, welfare services, old age pension, legal service and medical care, develop area specific community friendly memory clinics/community models
6.	Research and Development Develop/discover/deliver new innovative dementia friendly devices, processes, drugs
7.	Strengthen dementia disease surveillance system. Improve database/information management system through effective surveillance.

Based on the suggested actionable areas and its aligning with the WHO Dementia Global action plan, the suggested targets and corresponding activities are depicted in table:1 below:

Table 1 Dementia Targets and suggested activities

ACTION AREAS	TARGETS BY 2025	SUGGESTED ACTIVITIES
DEMENTIA AS A PUBLIC HEALTH PRIORITY	1. At least 30% of the states will have developed their own state programmes, strategies, by 2025	<ul style="list-style-type: none"> • Declare dementia as a national public health priority • Develop a comprehensive response through multi-sectoral approach • States to develop respective strategies and programs
DEMENTIA AWARENESS AND FRIENDLINESS	2.a) 80% of states where NGOs like ARDSI has chapters will have at least few functioning public-awareness campaigns on dementia to foster a dementia inclusive society by 2025. b) 50% of states will have at least few dementia-friendly initiatives c) 50% of states shall have stakeholder specific sensitization guides/manuals	<ul style="list-style-type: none"> • Promote healthy self-life style awareness • Increase dementia literacy among public • Activities related to reduction of stigma around dementia • Integrate dementia awareness activities with other old age related events • Develop and ensure availability of dementia awareness multi-media packages customized to low resource settings.
	Financial implications: 0.5 % of HRD budget Rationale: Elderly population constitute approximately 10 % or 100million and people with dementia constitute 0.5% of elderly population.	

DEMENTIA RISK REDUCTION	3. a) Premature mortality reduction from NCDs-by 25% b) Alcohol consumption reduction by10% c) Reduce the rise of obesity and diabetes d) Physical activity increase by 10% e) Reduce the rise of blood pressure by 25% f) Reduce sodium intake by 30% g) Reduce tobacco use by 30% h) Receive drug therapy & counselling to prevent heart attack by 50% l) Improve availability, affordability of NCD medicines by 80% j) Reduce indoor air pollution related to solid fuel by50%	<ul style="list-style-type: none"> • Adopt at least in 50% of states literature related to comprehensive lifestyle manual, integrate ayurveda dimension and translate into local languages • Regulate alcohol consumption and guidelines for voluntary adoption by states • Establish at least 60% of NCD screening centres in all health care centres in all states • Develop policy measures for food processing; reduce tax and increase subsidy on food products; • Reduce salt intake • Promote physical activity in schools/better urban development to support physical activity. • Implement strategies to reduce transfat intake
<p>Financial implications: 0.5% of NPCDCS budget for dementia; Rationale: Elderly population constitute approximately 10 % or 100million and people with dementia constitute 0.5% of elderly population</p>		
DEMENTIA DIAGNOSIS TREATMENT, CARE AND SUPPORT	4. a).In at least 30% of the states, as a minimum, 40% of the estimated number of people with dementia are correctly diagnosed. b).In at least 30% of the states, full time (24X7) care for advanced stage patients are created. c).Capacities of 30% General Practitioners and paramedical staff get built through regular yearly training	<ul style="list-style-type: none"> • Ensure that all people with dementia diagnosis are having patient centric standard treatment care protocols • Ensure frequent audit of therapeutic interventions available for dementia care at levels of care • Assess and allocate required hospital beds at district level and state level for dementia care services • Extend the ambit of palliative care to people living with dementia. • Train medical persons/human resources to diagnose dementia and support services
<p>Financial implications: 0.5% of health budget for dementia Rationale: Elderly population constitute approximately 10 % or 100million and people with dementia constitute 0.5% of elderly population.</p>		
SUPPORT FOR DEMENTIA CARERS	5. 40% of states, where NGOs like ARDSI chapters are present, provide support and training programmes for carers and families of people with dementia by 2025.	<ul style="list-style-type: none"> • Transport subsidy • Medical care expenses • Health insurance provision • Establish dementia home care service centres in collaboration with non-government institutions or independently in each district • Incorporate a chapter in school curricula as a part of old age issues with special emphasis on dementia • Judiciary to draw up standard procedures for civil disputes related to dementia affected people • Special provision for civil dispute/property settlements in relation to persons with dementia • Old age pension scheme inclusion of all persons with dementia
<p>Financial implications: 0.5% of social welfare budget for dementia; Rationale: Elderly population constitute approximately 10 % or 100million and people with dementia constitute 0.5% of elderly population</p>		

<p>DEMENTIA RESEARCH AND INNOVATION</p>	<p>6: The national and regional researches are augmented by 30% of current levels, on dementia patient centric care, to improve their living conditions, support from research organizations such as Indian Council for Medical Research (ICMR), Department of Science and Technology (DST), Department of Bio-Technology (DBT) and also funded by private stakeholders having interest in dementia research.</p>	<ul style="list-style-type: none"> • Mobilize financial resources to prepare, to test and to evaluate cost benefits analysis and exploring and including assistive devices, techniques, processes to support dementia friendly institutions. • Prioritized dementia relevant clinical trials, community trials, cost effective analysis and systems-policy analysis • Promote systematic review on cost effectiveness of the assistive technologies, processes in treating people with dementia • Develop resources mobilization hubs to discover new treatments, processes or new dementia friendly models
<p>INFORMATION SYSTEMS FOR DEMENTIA</p>	<p>7: 30% of states routinely collect a core set of dementia indicators through a national registry incorporating health and social information</p>	<ul style="list-style-type: none"> • Establish sentinel dementia surveillance system in 50 % of districts in each state • Dementia data analysis for descriptive, diagnostic, predictive and prescriptive purpose of dementia

Dementia India Strategy policy enablers to have convergence in strengthening dementia relevant services

- **The Maintenance and Welfare of Parents and Senior Citizens Act, 2007**
The act was enacted in December 2007 to ensure need based maintenance for senior citizens. The act suggests at least one old age home in every district with capacity of 150 persons in each centre.
- **National Policy for Older Persons (NPOP) 1999:** The policy envisages state support in areas such as: financial; food security; healthcare; nutrition; shelter; education; welfare and protection of life and property.
- **Central Sector Scheme of Integrated Programme for Older Persons-Revised (IPOP) 2016:** This program's objective is to strengthen the elderly people's quality of services such as food, shelter, and medical care, encourage productive and active ageing.
- **Inter-Ministerial Committee on Older Persons:** In order to strengthen NPOP, there is an inter-ministerial committee on older persons, to implement and supervise the elderly programs.
- **National Old Age Pension (NOAP) Scheme 1994:** The scheme is envisaged to improve economic status of senior citizens above the age of 65 years who have no financial support.
- **National Programme for Health Care of Elderly (NPHCE):** The key objectives are to identify problems in elderly people, access to preventive, rehabilitative services; build capacity of professionals; improve referrals; dedicated beds in district hospitals; develop 8 regional tertiary care centres for elderly persons and; reorient medical education.
- **National Policy on Senior Citizens 2011:** Suggests to sustain dignity of old age, mainstream senior citizens; improve institutional care; strengthen long term care savings and; set up homes with assisted living facilities.
- **National Program for Palliative Care:** National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS);

The Way Ahead

Dementia is becoming a national public health challenge. This demands a variety of relevant strategic actions for people with dementia and their family carers. The Dementia India Strategy document thus identifies dementia relevant core values and guiding principles, orientations, and strategies aimed at achieving the highest standard of dementia care services in India. It also outlines comprehensive dementia strategy implementation framework to achieve the stated policy vision and guiding public health principles such as prevention/risk reduction, early detection-diagnosis, access to best medical care, social support services, dementia research and information system. The document attempts to delineate the roles of different stakeholders from different sectors in delivering dementia care services and details the institutional management arrangements under the devolved system of government, taking into account the specific roles of the various ministries. Finally, this document provides a structure that harnesses and gives synergy to WHO's Global Action Plan on Dementia – Call for Action in ensuring dementia service delivery at all levels of government.

References:

- WHO (2017) WHO Global Action Plan on the public health response to dementia 2017-2025.
- ARDSI (2010) The Dementia India Report 2010, ARDSI.

ALZHEIMER'S & RELATED DISORDERS SOCIETY OF INDIA (ARDSI)

National Voice on Dementia since 1992

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