

Alzheimer Scotland Centre for Policy and Practice



Scoping Dementia Services and Public Health Data

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Developing community capacity to provide care for people with advanced dementia in India

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Scoping Dementia Services and Public Health Data

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Project Overview

This short report is one of a series of reports arising from a study funded by the Scottish Funding Council Global Challenge Research Fund. The Project "Developing family and community capacity to provide evidence-informed advanced dementia care, and reduce risks of dementia related elder abandonment and abuse" was co-delivered as a partnership project between the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland UK and the Manipal College of Nursing India. The Project responds to an urgent development need within India to develop dementia education aligned with the Global Sustainable Development Goals. The Project objectives focus on how advanced dementia is understood and experienced, the availability of advanced dementia care education and considers the potential usefulness of an existing portable education resource known as Class in a Bag.

This short report contextualizes dementia in India as a public health concern and scopes the current provision of dementia care services.

A Global Challenge

There are currently an estimated 50 million people diagnosed with dementia worldwide, approximately two thirds of these people are living within LMICs (ADI 2015). Numbers are projected to rise to 75.6 million by 2030 and 135.5 million by 2050. Each year £818 billion is spent on dementia with additional and often hidden costs met by families and unpaid carers. The economic burden is huge as is the personal challenge to people whose lives are affected by dementia.

Dementia is the 5th leading cause of death, contrary to popular belief in some regions, dementia is not a normal part of ageing it is a condition caused by illnesses such as Alzheimer's disease, which damages the structural and chemical integrity of the brain. Dementia has a profound impact on both those with a diagnosis and those who support them. Dementia symptoms depend on a number of factors including the underlying disease pathology, comorbidities and other factors relating to health, personality, biography and social-economics. Dementia is a progressive condition that affects memory, thinking, orientation, language and other higher cortical functions of the brain, and for some is associated with changes in emotional control and social behavior. Dementia contributes significantly to disability in late life and is major source of carer psychological distress (de Abreu et al 2018).

Currently there is no known effective treatement or cure and people can live for many years after diagnosis. The progression of dementia is often separated into mild, moderate and severe (corresponding to early, mid and late stage /advanced dementia). In the later stages of dementia healthcare needs are complex (Hanson et al 2016) and it is recommended that the needs arising from advanced dementia are seen as a continuum of dementia specific palliative care needs that include but are not confined to death and dying (Tolson et al 2016).

The projected increase in numbers of people with dementia make it imperative that LMICs prepare their health and social care workforce, create service models and care infrastructures to provide people with dementia with appropriate support across the illness trajectory. This support includes mechanisms to sustain family caring and to create supportive dementia aware communities.

Making Dementia a Public Health Priority in India

The World Health Organisation (WHO), Global Action Plan on the public health response to dementia, proposes that countries embrace national targets for increased dementia public policy, awareness, prevention, diagnosis, care and treatment and research (WHO 2017).

National dementia action plans are seen by WHO as central to the achievement of national dementia targets. A phased approach to developing and implementing a national dementia action plan is recommended by WHO (2018). Phases should include preparations that define the scope of the plan, followed by development of a strategic framework, which involves prioritization, agenda setting and resource identification, and a final phase concerned with operational delivery and evaluation. An important message from the WHO guidance is that decisions need to be made about whether or not to create a discrete dementia plan or an integrated dementia plan that is arguably resource efficient.

For countries like India, who are yet to produce a comprehensive dementia plan, dementia prevention is undoubtedly a priority but so too is the call for a public health and service response that enables people with dementia and their family carers to live well and receive the care and support they need. Alzheimer's and Related Disorders Society of India (ARDSI) (www.ardsi.org) is leading on stakeholder consultations to inform the development of a country action plan for India. Inclusion of India in the WHO knowledge exchange platform Global Dementia Observatory

https://www.who.int/mental_health/neurology/dementia/Global_Observatory/en/ this initiative will undoubtedly strengthen the availability of data about dementia in India, which is critical to dementia action planning. Currently available data on dementia in India is of varied quality and may underestimate the scale and complexity of dementia related needs and hardships. Dementia friendly community initiatives such as the Oormakootam campaign, using folk media, promoted by ARDSI, are important in that they pave the way towards progress and are indicative of growing public support for changes that can be achieved through strengthening of dementia capabilities within the community

(https://www.alz.co.uk/dementia-friendly-communities/india-way-forward).

A recent cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia conducted by Abreu et al (2018) revealed that dementia is all time a public health concern. They explored the relationship between caregiver burden, psychological distress, frailty and functional dependency of a relative with advanced dementia. Tools such as the Clinical Dementia Rating Scale, a sociodemographic questionnaire, the Zarit Burden Interview, the Brief Symptoms Inventory and the Edmonton Frail Scale were used. Alzheimer's disease was the most common type of dementia among the recipients of care, who showed moderate (42.2%) to severe (52.9%) dementia. Among them 35.3% exhibited moderate and 45.1% severe frailty. Family caregivers reported moderate (76.5%) to severe burden (18.6%). Psychological distress was very high among family caregivers. Results show that people with dementia exhibited moderate (35.3%) or severe frailty (45.1%) and that a severe frailty was found in people with moderate dementia. It is clear that advanced dementia has a profound impact on family wellbeing and that strategies are needed to help both the individual with advanced dementia and their caring family.

What follows in this short report is a selective and descriptive contextual overview intended to serve as a resource for those at the start of action planning and service development journeys.

Dementia in India

India is the second highest populated country in the world with a predicted population of older people of 179 million by 2031, rising to 301 million in 2051. As more people are living longer dementia is increasing and is now considered as one of the emerging public health challenges (Sinha, 2011). As per 'dementia India' report published by Alzheimer's Disorder Society of India claims 4.1 million cases in India and is expected to double by 2035 (Baste 2019). Mahararshtra and Utter Pradesh are expected to house more than 5,000,000 patients by 2026. Public awareness of dementia is low and this leads to delayed help seeking and often late diagnosis.

Krishnamoorthy et al (2014) offers a detailed discussion of risk factors associated with different dementia sub types in India and also explores 'reversible dementias' which are caused by substances such as alcohol and medication related.

There are relatively few robust dementia prevalence/incidence studies from India (e.g. Chandra et al 2001, Raina et al 2009) and it is beyond the scope of this report to present epidemiological data in detail. We do however note that studies have highlighted regional differences in dementia incidence in India. In some Indian states a 200% increase in the number of dementia cases has been projected (Krishnamoorthy et al 2014). A ten year prospective study found a much higher incidence of Alzheimer's disease in southern India than previously reported from the rural north (Mathuranath et al, 2012). Interestingly a recent community based study from Kolkata reveals an overall low prevalence and incidence of dementia than in developed countries, but a high premature mortality associated with dementia (Banjeree et al 2017). It is possible to speculate that some of the reported premature mortality may be associated with advanced dementia related hardships, including poor care and in some cases neglect and possibly abuse.

Treatment Gaps

There are no accurate estimates for the treatment gap for dementia in India, but analysts have suggested that this gap exceeds 90% in most parts of the country, with the exception of urban areas and the two southern states of Kerala and Tamil Nadu We do have relatively accurate estimates of the treatment gap from Goa. In a recent study in which 81 subjects with dementia participated, although 41 (51%) were seen by a doctor in the previous three months, only 4 (5%) had received the diagnosis and treatment specific for dementia. Thus, the treatment gap was over 90%, even in this relatively prosperous state of India with relatively good public health and mental health services. The study also reported that some families refused to take dementia specific medications mainly citing reasons including high cost, the family doctor advising not to take the medications, and fear of side effects (Dais et al 2009).

Dementia Care in India

The Centre for Disease Control (CDC) in collaboration with Alzheimer's association, have identified the following four elements as foundational for quality dementia care:-

- **Educate and empower:** creating awareness to public regarding brain health, best available practices, role of caregivers, prevention of abuse and neglect, tools to help caregivers, and improve access to dementia care services.
- Assure competent works force: health professionals with adequate reliable information for care givers, health promotion, continuing education, competencies in care, treating comorbidities, and assessing health risk.
- Develop policies and partnership: putting forth effective intervention and best practices, assuring academic programs, informed decisions in place, cognitive assessment as part of health care quality assurance, engaging private public partnership and emergency preparedness.
- Monitor and evaluate: to implement the behaviour risk factor surveillance system, national data collection on dementia and caregivers, use of data to inform public and create awareness, evaluation and training and care giver support system and estimate the gaps between works force capacity and anticipated demands (Anderson & Egge 2014).

The following section provides a selective overview of existing dementia care services in India. From the available information on these services we have not been able to identify care standards or evidence based care protocols guiding practice and there does not appear to be provision of training to support family caring.

Dementia Care Facilities in India

The predominant form of care for people with dementia is family caring, with responsibilities often falling to daughter-in-laws (Das et al., 2014). In Indian context 70% of the health care expenses are met from the pocket and through the insurance system. This creates difficulties for people experiencing neuroprogressive conditions such as dementia and to financial and other constraints, many are lost to follow up care.



Fig: 1 Mapping of public dementia care facilities across India

It is recognised that available public services for the 4 million people living with dementia across India are inadequate. Current dementia specific services include approximately 100 memory clinics, 10 day care centres, 6 residential care, 6 domiciliary services and ten dementia help lines facilities (Krishnamoorthy et al 2014). Figure 1 maps the location of key public dementia care services in India.

Dementia Care and Dementia Information Centres do exist but there are regions, which do not appear to have dedicated Centres. The online Dementia Care Notes Resource https://dementiacarenotes.in/resources/city-wise/ lists day care facilities, respite and continuing care services and provides contact details for telephone helplines. What is unclear from these lists is how families can determine the quality of the services or judge the trustworthiness of available information. Appendix 1 provides summary information about some of the established services to illustrate the type and scope of provision that is currently available in some areas, albeit serving a relatively small number of the people who need such services.

It is difficult to discern how the staff who work in such centres are prepared and supported to meet the needs of people with dementia or advanced dementia as there is no readily available information on staff qualifications or provision of training. Information about the quality of care is not readily accessible and there seems to be an absence of care standards to guide the care or facilitate the monitoring of care quality provided to patients with dementia or advanced dementia.

Similarly there appears to be a reliance on untrained personnel for daily care within family home. Across all care settings skill mix, inadequacies in staff training and the lack of access to expert dementia care professional support will increase the likelihood of sub-standard practice and care that is well intentioned but ill informed. Furthermore this situation increases exposure of vulnerable people with dementia to the risks of neglect and dementia related abuse.

Conclusion and Recommendations

Although it would be desirable to have more accuracy and insight into the dementia population statistics and projections across India there is no doubt that dementia is a significant and growing public health challenge, as it is elsewhere in the world. The projected increase in the numbers of people with dementia in the next few decades in India, make a compelling case to prioritise attention and resource on dementia through establishment of a national action plan.

There are currently an estimated 4 million people living with dementia in India and an urgent need to establish care services and dementia education aligned with the Global Sustainable Development Goals. There is an immediate need to improve dementia awareness across India and to establish a comprehensive dementia care infrastructure aligned with the Global Sustainable Development Goals. To achieve this will require workforce development for health, nursing and social care practitioners supported through the establishment of centres and frameworks for excellence for dementia education and practice.

This scoping review gives insight into the scale of dementia related needs and the lack of attention afforded to advanced dementia. Advanced dementia within India is a hidden problem which places individuals and their sometimes young carers at high risk of poverty and other

inequalities. There is an immediate need to develop practical and theoretical understanding among practitioners, policy decision-makers and the public about advanced dementia alongside an understanding of advanced dementia-related abuse and abandonment.

There is no doubt that the Indian dementia care scenario is in its infancy stage and steps need to be taken to address the needs of both individuals and family carers affected by dementia.

To make progress we need evidence to achieve understanding of the challenges and burden faced by family caregivers and strategies which include family carer education and supportive infrastructure. Research is also necessary to fully understand how the rights of people with dementia are met, and to understand how individuals living in the family home and patients using services experience care including advanced dementia care. It will be important to generate a realistic and grounded understanding of practice at its best and of dementia related hardships, which will inevitably include understanding manifestations of abuse, neglect and abandonment. Such an evidence informed understanding will propel improvement strategies and enable focus on immediate and priority issues. Movement with community will make sense and hence the project team would sincerely work towards a framework with standardized protocols and provide capacity building training services for quality care and education across the health sector in India.

In the third of our short reports in this series we focus in more detail on dementia education and highlight major gaps in practitioner education with particular attention to meeting the needs of people with advanced dementia.

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Appendix 1 Overview of Existing Dementia Services in India

1. ETCM - Nightingales Dementia Care Centre, F Ward, ETCM Hospital, Bangarpet Road,, Kolar, Karnataka 563101

Facilities:

- Total bed strength of 48
- 24 hours services provided to dementia patient
- First telemedicine enabled care facility in India located in Ellen Thoburn Cowen Memorial (ETCM) Hospital
- Single floor extended to a garden and terrace, walking space, colourful rooms with detailed activities to suit their care environment.
- One of the advantage of this facility is that the dementia centre in within the hospital facility that takes care of all medical emergencies are handled immediately in the hospital.

2. Comprehensive Dementia Day Care Center _ ARDSI Ayyampilli Mana Rd, Eroor North, Eroor, Ernakulam, Kerala 682306

Facilities

In September 2014, the Kerala State Government State took cognizance of dementia as an issue that needs a specific health strategy, separate from general geriatric care, and began initiatives to handle this. A public-private joint venture of Govt. of Kerala and the ARDSI National Office, Kerala State Initiative on Dementia, has started projects under the name: Smruthipadham, with the first being in May 2015.

Expansion to other districts

Districts	Details
Kunnamkulam (Thrissur district)	ARDSI (Alzheimer's and Related Disorders Society of India) is one of the main resources for dementia caregivers in India.
ARDSI National Admin Office National Office of Alzheimer's and Related Disorders Society of India)	Contact ARDSI National Administrative Office:Alzheimer's and Related Disorders Society of India Guruvayur Road, P.B.No. 53 Kunnamkulam – 680 503, KERALA

Smruthipadham (Kerala State Initiative on Dementia) Day Care, (Thrissur district)	Smruthipadham (Kerala State Initiative on Dementia), a public-private joint venture of Govt. of Kerala and the ARDSI National Office, has a day care centre in Thrissur, at: Day Care KSID Smruthipadham Dementia Care Centre, Kurukkenpara Via, Kavilakkad, Chittanjoor, Kunnamkulam – 680 503
Dementia Respite Care Centre (Harmony Home) (Thrissur district)	Dementia Respite Care Centre (Harmony Home) Offers full-time respite care. Set up with the support of various Rotary Clubs and other bodies, it is now fully managed by ARDSI National Office. 24 x 7 Care Home Dementia Respite Care Centre (Harmony Home),, Ramavarmapuram P. O, Villadam, Milma stop, Thrissur -680 631 Kerala
ARDSI Calicut (Kozhikode) Chapter and Malabar Harmony Home respite care Calicut/ Kozhikode	Malabar Harmony Home address (relocated to this in December 2016) is: Malabar Harmony Home (ARDSI), P O Marikunnu, Near NGO Quarters, via Ambalaparambu Colony, CALICUT – 673 012, Kerala.
ARDSI – Kochi (Cochin) Chapter and their Day Care Centre, and Cochin Harmony Home (Ernakulam district)	ARDSI – Kochi (Cochin) Chapter Dr. Mathew Abraham, President, Consultant Neurologist. The updated chapter details and functions can be obtained from the Comprehensive Day Care Centre listed below. Cochin Harmony Home: This respite care/ full-time facility is managed by ARDSI National Office
Smruthipadham, Full-time dementia care, Edavanakkad (Ernakulam district)	A full-time Dementia Care Centre has begun functioning in Edavanakkad, Ernakulam since 20th May, 2015. This is part of the project, Kerala State Initiative on Dementia, a public-private joint venture of Govt. of Kerala and the ARDSI National Office (Alzheimer's and Related Disorders Society of India). The center provides 100% free service to poor (below poverty line) senior citizens and persons with Dementia. And also a full time(day time only) ayurvedic doctor has been appointed in the center. Social investigation of applicants is done to check eligibility for this centre.
Signature Aged Care Ernakulam	Signature Aged Care is a home for the aged & terminally ill. They accept persons who require nursing assistance on a day to day basis, including persons with problems like dementia and stroke. They accept persons for both short-stay and long-term stay. They have physiotherapy, full nursing support and regular doctor visits, etc., and provide "no bystander needed" personalize care. They use consultations with medical experts and hospital visits, etc., as needed, and also have palliative care support. The care home is managed by a private no-profit no-loss trust.
Clinic at Bethesda Hospital, Perumbavoor (Ernakulam district)	Bethesda Hospital: This psychiatric hospital admits persons with dementia after consultation with Dr. S Shaji. Contact: Bethesda Hospital, Vengola, Perumbavoor, Ernakulam

	RDSI – Pathanamthitta Chapter , Kaithavana Building, Thekkemala P.O, Kozhanchery, Pathanamthitta – 689 654, KERALA
Disorders Society of India) Trivandrum Chapter Chapter	RDSI – Trivandrum (Thiruvananthapuram) Chapter and their respite care 24 x 7 Care Home Snehasadanam Respite Care, Lions Bhavan, N.H.Bypass Road, Thiruvallam, Thiruvananthapuram – 695 027,KERALA
	Other care centers
	CanCare Kochi, Amra 160, Mavelipuram (West), Thrikkakkara, Cochin, Kerala, 682 030 Phone: Call: 0484- 2428 999 Mob: +91 9497 380 999 / 9497 380 888 Web: www.cancarekochi.com
	Caremark India, Office suite 106, 4th Floor, Crescens Tower, Changampuzha nagar P.O, South Kalamassery, Cochin- 682033 Phone: +91 9539889989 Email: cochin@caremarkindia.in Web: www.caremarkindia.in
	Guardian Angel Homecare (P) Ltd., 34/448, Pipeline Road, Padivattom, Kochi, Kerala, India – 682024 Phone: + +91-484-2806869 / 8589098181 Email: customercare@gahc.co.in Web: www.gahc.co.in Red Cross, Kottayam Provides 24-hour attendants for some cities in Kerala. Contact: Indian Red Cross Society, Kottayam District Branch, Red Cross Tower, Nagambadom, Kottayam-686001, Ph: 0481-2300238, 0481-2560238
	India Home Health Care (IHHC): (Chennai based) (partner of BAYADA Home Health Care)
	Services
	Training care giver / attenders24 hours service

3. Jagruti Dementia Care, Senior Living Home & Assisted Care, Zagade Vasti, Solapur - Pune Hwy, Maharashtra 412307

Services

- Policy is to provide World Class, Comprehensive, Convenient, Timely & Compassionate Care & Treatment at reasonable cost Facilities We have Private (single) & Semiprivate(Two Sharing) rooms.
- The rooms are warm and welcoming. People can bring their own personal belongings, which they are welcome to do as it helps them to feel more at home and more comfortable'
- Facilities for persons with Alzheimer's/ other dementias. Dementia-related material in various Indian languages (including Marathi). General tips for locating relevant resources in a city.

Dementia Helplines

- Pune Police Senior Citizens Helpline: Run by the Commissionerate of Police, Pune, and Athashri Foundation: 020-26111103 (working days, working hours) For emergency outside these hours, use the normal police emergency number, 100.
- Helpage helpline: All-India toll free number: 1800-180-1253. Pune number: 020-20265513
- Dignity helpline: Senior citizen helpline at +91 20 26851221, Mon-Fri, working hours, run by Dignity Foundation
- Nightingales centre for ageing & alzheimer's & elders enrichment centre

 nightingales medical trust, 8P6, Kasturinagar, 3rd A Cross Rd, East of
 NGEF Layout, Banasawadi, Bengaluru, Karnataka 560043

'Established in 2010, Nightingales Centre for Ageing and Alzheimer's (NCAA) is India's largest comprehensive residential care centre. This 98 bed facility provides the whole range of services required to manage Dementia under one roof. All the features essential to a dementia-friendly facility, so as to encourage independence and social interaction, promote safety and enable activities of daily living are incorporated in this 4-storied building. A central courtyard, lawn, paved walk, gazebo, water fountain and a garden provide a quiet oasis for the residents. This Centre also houses the Elders Enrichment Centre at Kasturinagar where elders gather daily to involve in physical, social and cognitive activities including yoga and aerobics

Other centres in Bangalore

 Nightingales Trust Dementia Day Care Centre - KR Market round Floor No.
 40, Lakshmi Complex, KR Fort Road, Opp Vanivilas Hospital, Bengaluru, Karnataka 560002

- Nightingales Trust Dementia Day Care and Active Ageing Centre RT Nagar, Bangalore No. 337, 2nd Cross Rd, 1st Block, Rahmath Nagar, RT Nagar, Bengaluru, Karnataka 560032 (Day care centre)
- 5. Dignity Dementia Day care Centre 136/52, Block AK, 136/52, 7th Main RoadN Rd, MGR Colony, Anna Nagar, Chennai, Tamil Nadu 600040
 - Day care centre (10 am- 3pm) in Chennai for people with dementia.
 - Patients are given occupational therapy, daily activities to improve their memory power, Yoga and exercise, mind relaxing activities etc. Staff are very caring and loving the patients. It starts by 10 AM to 3 PM
- 6. Samvedna Senior Care, G-7, Sushant Lok III Extension, Sector 57, Gurugram, Haryana 122002
 - Samvedna senior care provides stimulation and it is the center which helps seniors dealing with dementia and depression problems