

DEMENTIA FRIENDLY KERALA — THE WAY FORWARD

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ABSTRACT

Dementia is a major cause of disability and dependency in old age. Compared to other Indian states, Kerala has one of the highest proportions of elderly in the country. However, there is poor awareness about dementia among all sections of our society. There should be a concerted effort to educate the public and to develop services that improve quality of life of dementia patients. Professionals have to be trained and made confident in understanding and skilled in addressing the problems associated with dementia. There is a need to develop specialized dementia care services that can be implemented using the existing infrastructure. The Kerala model of health care, a remarkable achievement at par with those of many developed countries, is ideal for developing a dementia care initiative that can serve as a model for other Indian states. Health, social welfare, and social justice sectors should jointly design a service stream for dementia sufferers. Voluntary agencies can play a close collaborative role in this model of care, and organizations like Alzheimer's and Related Disorders Society of India (ARDSI) are well positioned to do it, considering their experience and knowledge.

Keywords: Dementia- friendly, Kerala, Alzheimer's, DFC

Reports indicate that, in 2010, more than half (57.7%) of all people with dementia lived in low and middle-income countries. This proportion is expected to rise to 63.4% in 2030 and to over 70% in 2050. The joint

report by the World Health Organization and Alzheimer's Disease International which published these figures has gained wide international attention.¹ This data underline the need for programs that focus

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on improving early diagnosis, raising public awareness about the disease, reducing stigma, and providing better care and support to caregivers.

DEMOGRAPHIC TRANSITION

India has one of the highest proportions of elderly population in the world.² Dementia is one of the major causes of disability and dependency in old age.³ We have significantly moved on from the time when many believed that Alzheimer's disease is an illness of the West. Still, the illness is widely under-recognized in our country due to lack of awareness and information about it.³ According to the Dementia India Report 2010, 3.7 million people in India are affected by dementia, and the number is predicted to increase to 4.41 million by 2015.³ Due to the steady growth of older population and the stable increase in life expectancy, this figure is expected to double by 2030 and triple by 2050.³ It will be impossible for the government health systems to address the predicted increase of prevalence and associated costs of caring. There should be a massive drive to increase financial and manpower investments in health and social care to improve the services for people with dementia.

Kerala, however, also has a unique problem to deal with. Compared to the national figure of 8%, in Kerala, people above the age of 60 constitute 12.6% of the population.⁴ This has to be seen in the backdrop of a declining population growth. While India's population grew by over 17% between 2001 and 2011, the growth rate in Kerala was just under 5%.⁴ In addition to the growing number of elderly, the numbers of young and abled who are to look after them continue to decline. The safety net for elderly care in the form of multi-generational joint families is fast

disappearing due to urbanization, modernization and economic migration, resulting in more nuclear families than ever. There have been a few studies estimating the prevalence of dementia in Kerala.^{5,6,7} By any conservative estimate, there are well over 1.5 lakh people with dementia in the state. The widely acknowledged Kerala model of health care, which is a remarkable achievement at par with that of many developed countries, may also prove to be the best launch pad to develop a dementia care initiative.

IMPACT OF DEMENTIA

Dementia is a devastating condition that robs all mental faculties of the affected, progressively rendering the person completely dependent on others for even the most basic activities of daily life. The relatives do not recognize the person with dementia as the same person they have known before, due to the marked changes in the personality and behavior brought by the disease. The illness causes significant strain on the mental and physical health of the primary caregivers: often partners, siblings, children or daughters-in-law.³

IS THERE ANY HOPE?

The current lack of curative treatments should not be a reason for laxity in early diagnosis and interventions. Much can be done to reduce the burden of the disease on the persons and the families by early interventions like improved awareness and medical, psychosocial and behavioral interventions. There is some scope for medications, especially in the early and middle stages of the illness. Medications are also effective in managing the common problem of behavioral and psychological symptoms associated with dementia.⁸ Psychosocial interventions aimed at

educating the caregivers on managing the behavioral problems associated with dementia too have been found to be effective.⁸

CREATING DEMENTIA FRIENDLY COMMUNITIES

We suggest the following approaches to create a dementia friendly society, based on our experience as a professional organization working for the welfare of people with dementia and their families:

(i) Awareness: There is poor awareness about dementia among all sections of the society.³ The public should be made aware that symptoms of dementia are not a part of normal ageing, but signs that tell them to seek medical help. Lack of understanding leads to stigma and negative attitudes, which in turn result in families not seeking medical help or assistance.

Families frequently report the difficult journeys before receiving a diagnosis of dementia, emphasizing the need for specific training in dementia for all health and social care professionals, including doctors, nurses, community health workers and social workers. We need a breed of professionals who are confident in understanding and addressing the problems faced by families of dementia patients. Though diagnosis of the condition and prescription and monitoring of memory medications are specialist skills, we strongly believe that the general care of dementia is a responsibility all healthcare professionals should be ready to shoulder. All health care staff should be educated on when to suspect dementia, as all of us are bound to see someone with dementia wherever we work or whatever we do, even if we do not provide specialist dementia care.

(ii) Services: We should improve the quality of services available to people with dementia. There should be joint efforts by the health, social welfare and social justice sectors to design a service stream for people with dementia. We have learned from the experience of other countries that comprehensive intersectoral collaboration is essential to effectively address the problems in dementia care.⁹ The course of the illness, from onset of symptoms to the final stages, can aptly be called a “dementia journey” which the family does along with the patient. There should be support available at all points in the dementia journey, which starts from the first symptoms like lapses in memory and changes in mood and personality. When they arrive for a consultation even at a primary care level, the professionals should have the skills and knowledge to complete an assessment. It is extremely important at this early stage to rule out any reversible causes of dementia. Most of these patients would need a specialist referral to confirm the diagnosis and start medications if appropriate, and their mental status, cognitive functions, behaviors, level of functioning, and care needs will need monitoring.

(iii) Specialist Care: There is a need to develop specialized dementia care services, and this can be done using the existing infrastructure in general hospital settings.¹⁰ Specialist assessments can be conducted in Memory Clinics (dementia clinics). Currently, very few such facilities exist. Memory Clinics are multidisciplinary teams led by specialist doctors (usually psychiatrists or neurologists), and can consist of nurses, social workers, psychologists, occupational therapists, etc. Periodic (eg. weekly, fortnightly) Memory Clinics run by professionals trained in dementia care can provide dedicated service in higher level centers like Taluk and

District Hospitals and Medical Colleges. Hospitals in private sector can follow the model within their existing systems without much difficulty. These clinics should have easy access to inputs from specialists in psychiatry, neurology, general medicine and radiology.

As the disease progresses, families will need advice on managing challenging behaviors and deteriorating activities of daily living. While the medical specialist takes a lead role in prescription and monitoring of medications, nurses can advise the families on various nursing aspects of dementia care. Other members of the multidisciplinary team, including social workers and psychologists, can play a major role in psychosocial interventions.

(iv) Day Centers and Residential Care: As the dementia journey continues, families often find services like day centers increasingly helpful. As the social landscape of our family systems is undergoing massive changes, with disappearance of joint families, migration, and increasing prevalence of families just comprising of an older couple, the relevance of domiciliary care, respite centers, and 24-hour care centers is increasing. This is an area which needs close attention of government and non-governmental organizations. Alzheimer's and Related Disorders Society of India (ARDSI) has been in the forefront as a registered national, non-profit, voluntary organization engaged in the care, support, training and research of dementia since its inception in 1992. ARDSI is actively involved in developing services — currently there is a Day Centre (Cochin) and three full time care homes (Cochin, Kunnampalam, Calicut) for people with dementia run by the national office in Kerala, and another center is being run by the Trivandrum Chapter.

The viability of a business model in this sector has drawn many major players into the scene, and probably the future depends on the strength of the social commitment as well. The societal attitude towards care homes for the elderly has been on a changing course. Many now are open to the reality that it is not only acceptable, but in some situations essential, to look into such options to provide quality care for the elderly.

(v) Palliative care: Dementia, by nature, is a progressive illness, and the condition of the sufferers is bound to deteriorate over a few years' time. Palliative care in advanced dementia has been receiving attention all over the world.¹¹ It is essential that we acknowledge the need to discuss this important issue, and deliberate on vital aspects like how invasive should the management be in someone with a terminal condition.

COLLABORATIVE APPROACH IN CARE AND SERVICE DEVELOPMENT

Voluntary organizations play a close collaborative role in dementia care. Training of existing lay health care workers is an important strategy found useful elsewhere.¹² Programs can be successfully integrated with existing government schemes like Vayomitram, which provide health care and support to elderly people, if properly conceived with provisions for appropriate training. A horizontal integration of District Mental Health Program (DMHP), which is now functional in all districts in Kerala, with Palliative Care Program, supported by the local self-governments, is a model scalable across the state.¹³

There are several examples of effective collaborative approaches across the world in creating dementia friendly communities (DFC). A notable example is from the United Kingdom where the Government has joined hands with the Alzheimer's Society and other key partners in defining and developing this concept.¹⁴ The program focuses on improving inclusion and quality of life of people with dementia.

Despite the magnitude of the problem and the enormity of the challenge, dementia has not yet received the due attention at a socio-political level. However, recently there have been several positive responses from the government in recognizing the need to support dementia care and services in Kerala in the form of Kerala State Initiative on Dementia (KSID).¹⁵ This is the time to gather momentum to tackle the challenges of dementia through partnerships. There should be a concerted effort to educate public, train professionals, and develop services to improve the quality of life of those affected by dementia. We have to use an asset based solutions strategy, working on to build on existing manpower and resources for the program to be successful. Commitment and belief in the cause will be the major determinants of the progress of any strategy to address this problem we can no longer ignore.

STRATEGIES FOR A DEMENTIA FRIENDLY KERALA

To summarize, the essential strategies to build a Dementia Friendly Kerala would include:

- Creating dementia awareness among the general public
- Educating and training health care professionals about dementia management

- Developing services to diagnose and manage dementia with equal emphasis on medical and psychosocial care
- Developing a pool of community workers and dementia friends to provide care and support at the point of need
- Working towards a state level dementia strategy and dementia care policy which should also focus on issues like legislation and financial assistance
- Employing risk reduction strategies at public health care level
- Close collaboration with all stakeholders, including government and non-governmental organizations, voluntary sector and private partnerships.

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