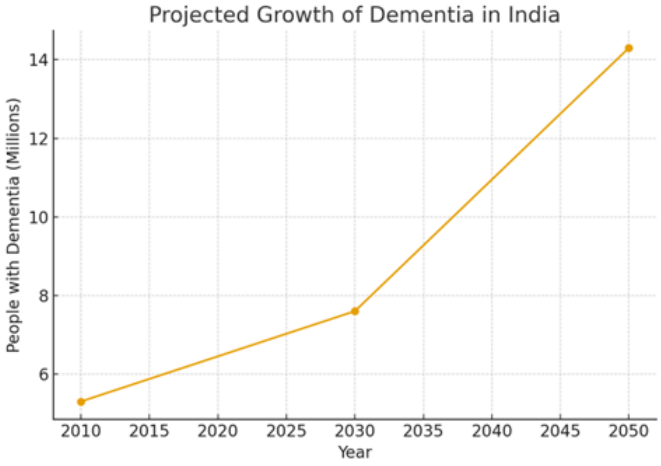
INDIA'S DEMENTIA CARE CRISIS

Dementia is rapidly emerging as one of India's most significant public-health challenges, driven by demographic ageing and the rising burden of chronic disease. Dementia is defined as a chronic, progressive syndrome characterised by the deterioration of memory, thinking, orientation, language, comprehension and judgement due to underlying brain disease. The most common types include Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia, which together account for nearly 80% of all cases[1]. While no cure currently exists, early identification and psychosocial interventions can slow progression and ease behavioural and psychological symptoms.

Recent estimates from the Longitudinal Aging Study in India – Diagnostic Assessment of Dementia (LASI-DAD) suggest that 7.4% of adults aged 60 and above live with dementia, translating to approximately 8.8 million older Indians today [2]. Earlier projections from the Alzheimer's & Related Disorders Society of India (ARDSI) estimated 5.29 million people living with dementia in 2010, rising to 7.61 million by 2030 and 14.32 million by 2050, Yet despite this scale, fewer than 10% of people with dementia in many lower-middle-income countries, including India, ever receive diagnosis, care or appropriate treatment.



The disabling impact of dementia is particularly severe. Global Burden of Disease consultations assign dementia a disability weight of 0.67, one of the highest for any health condition, signalling a loss of nearly two-thirds of functional quality of life each year. Extensive work by the 10/66 Dementia Research Group has shown that dementia is the leading cause of disability and dependency in older adults, surpassing stroke, depression, arthritis, heart disease, hypertension and chronic obstructive pulmonary disease.

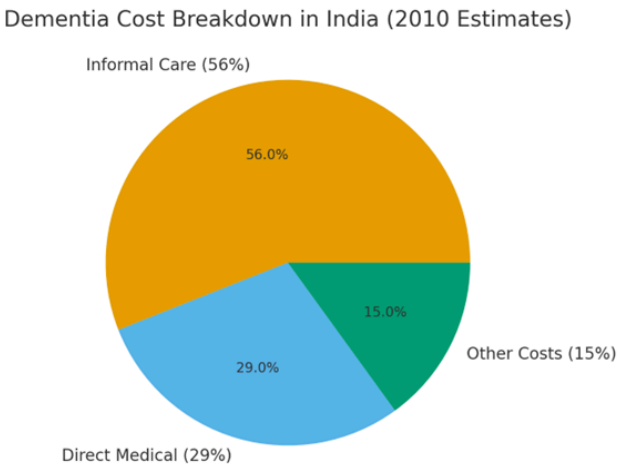
Understanding dementia in India therefore means understanding the people who carry most of its weight: the carers.

Caregiving has been described as the provision of extraordinary care that exceeds what is normative within family relationships, demanding sustained time, emotional energy and financial resources over many years. In India, caregiving is woven into complex social structures shaped by kinship, gender roles, intergenerational expectations and economic constraints. A multicentre study by the 10/66 Dementia Research Group, which surveyed 179 primary carers across Bangalore, Chennai, Goa, Hyderabad, Thrissur and Vellore, found that 75% of primary carers were women and 98% lived with the person with dementia. Extended families were common and 20–50% of households reported additional informal help, yet paid caregivers were almost non-existent in Indian sites. [3]

Across studies, the care needs of people living with dementia in India are consistently high. Between 50% and 70% require significant support with basic daily activities, and most need “much care,” meaning constant supervision and hands-on assistance. These needs are rarely met by trained professionals. Instead, family members step into caregiving roles suddenly, often without preparation, guidance or access to structured services. The psychological impact is striking: between 40% and 72% of primary caregivers report high levels of psychological morbidity, with symptoms of depression, anxiety and chronic stress[1] .A Recent study from India has further shown that dementia caregiving affects happiness, spirituality and overall well-being, with both primary and non-primary carers reporting emotional strain, and deep fatigue [4]

Traditional multigenerational households historically allowed elder care to be distributed across family members. Today, this model is going through intense changes. Migration, urbanisation and increasing labour-force participation, particularly among women, mean that older parents often remain in the village or home with shrinking support networks.

Dementia care in India is broadly divided into formal and informal care, but the reality is that informal care dominates. Formal care encompasses institutional services such as long-term residential facilities, nursing homes, memory clinics, respite care and community programmes. Informal care refers to unpaid care provided by family and friends, usually accompanied by lost income, ambitions and emotional exhaustion. While formal care can be costed and documented, informal care is methodologically difficult to measure because caregiving tasks are diffuse, hours fluctuate and lost productivity is hard to monetise. Nonetheless, informal care remains the backbone of dementia support in India.



The economic impact of this reliance on families is substantial. With an estimated 3.7 million people with dementia in 2010, the total societal cost in India was calculated at US$ 3.415 billion (INR 147 billion). Informal care alone accounted for 56% of this cost (INR 88.9 billion), while direct medical care contributed 29% (INR 46.8 billion), and the average cost per person was US$ 925 (INR 43,285). Urban households bore informal care costs more than twice those in rural areas because of higher opportunity costs and different care patterns. Subsequent modelling has estimated national dementia-related expenditures between US$ 9.4 and 13.7 billion, depending on caregiving hours, with direct care alone costing US$ 6.1 billion annually and costs rising steeply with disease severity[3].

More recent analyses, adjusting for inflation and updated prevalence, show that rural households spend between ₹29,272 and ₹95,208 annually on dementia-related care, while urban households spend between ₹65,755 and ₹2,91,933 each year, depending on severity and service use. These expenses disproportionately affect women, who often reduce or leave paid work to provide full-time care, converting dementia from a health condition into a gendered economic issue with long-term implications for, savings and financial security[5]

Dementia services remain limited and uneven across India:

At the same time, service availability remains limited and uneven. Day-care centres, respite services and long-term residential facilities are sparse and concentrated primarily in a few urban centres[6]

Families frequently learn about memory clinics or dementia organisations only through personal networks or chance referrals. In rural areas, primary healthcare providers often lack

training in geriatric mental health, and many public health centres do not recognise dementia as a distinct condition[1]

The broader elder-care infrastructure is equally inadequate for the scale of demographic change. A 2023 report by Samarth, Tata Trusts and UNFPA found that India has just 1,150 state-run senior-care facilities with capacity for around 97,000 older adults, in a country with more than 140 million seniors[7] The shortage of dementia-friendly care environments is even more acute. At the same time, India's senior-care market is expanding rapidly, driven by private and technology-enabled models, and projected to reach US$40–50 billion by 2030, but these services remain inaccessible to the vast majority of families who rely on the public system or out-of-pocket arrangements[8]

The everyday reality for carers is shaped not only by service gaps but also by stigma and lack of awareness. Community-based research in India reports that many caregivers and even healthcare professionals confuse dementia with normal ageing, stress, vitamin deficiency or psychiatric illness, while others interpret it through cultural or spiritual lenses such as karma or "spells." Local idioms such as "Sathiyana" (gone sixtyish) in North India, "Chinnan" (childishness) in Malayalam-speaking regions and "Nerva Frakese" (tired brain) in Konkani-speaking communities further illustrate how dementia is perceived socially rather than medically. Misconceptions extend into institutional settings, where nursing home staff may hold stigmatising beliefs about dementia, contributing to neglect, inappropriate use of sedatives or physical restraint, and inadequate engagement with the person's needs[1]

For carers, this means navigating a condition that is medically complex, poorly understood and structurally unsupported. Families often move from clinic to clinic without clear pathways, rarely receive structured counselling or carer training, and are left to manage wandering, aggression, incontinence, sleep disruption and communication breakdown with little or no professional guidance[3] Without respite care or psychological support, many carers internalise the burden, suppress their own needs and develop symptoms of depression and anxiety that go untreated[4]

India's broader health system context compounds these challenges. Public expenditure on health remains low at around 1.9% of GDP, and resource allocation for mental health and elder care is a small fraction of this already constrained budget[3] Older adults travel an average of 14.5 km for outpatient care and 43.6 km for inpatient services, with rural elders facing significantly greater distances and limited transport options; 95% of inpatient admissions rely on personal transportation[9]

Taken together, these patterns reveal a clear picture: dementia in India is not simply a neurological condition but a structural test of how Public health system values older people and those who care for them. Carers are the invisible backbone holding the system together. They absorb economic shocks, provide round-the-clock support, protect dignity and safety, and bridge the gap between an under-resourced health system and the complex needs of people with dementia. Yet their welfare, mental health and financial security remain largely absent from formal policy discourse.

A serious national dementia response must therefore be carer-centred. This means raising awareness in regional languages so that families can recognise early symptoms; integrating dementia screening and caregiver counselling into primary care; training health workers and community volunteers to support carers; expanding affordable day-care, respite and home-based services; and designing financial protection mechanisms that recognise unpaid caregiving as a critical social contribution[5]

It also means investing in research that documents carers' experiences, tests culturally appropriate interventions and informs policies that uphold both the rights of people living with dementia and the dignity of those who care for them[3]. A humane and prepared society acknowledges cognitive decline, supports families and builds systems that ensure no carer carries this burden alone.

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