

# Chapter 18

## The Status and Well-Being of Elderly Women Suffering from Dementia: Case Studies from Bengaluru



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**Abstract** Dementia, generally predominant among the elderly, is associated with the progressive degeneration in memory, thinking, and reduced ability to perform everyday activities. The impairment in cognitive function is commonly accompanied and occasionally preceded by deterioration in emotional control, social behavior, and motivation. As per the 2018 data, there are about 50 million people worldwide are living with dementia. The World Alzheimer's Report (2009) focuses on the global prevalence of dementia, its impact, and how it can be brought from recognition to action. Dementia patients were 35.6 million in 2010. The number will be doubling every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Of the people who have dementia worldwide, 58% live in low- and middle-income countries, which will rise to 71% by 2050. According to the Dementia India Report 2010, the prevalence of dementia is seen more among older women than older men. In India, the lack of a state-sponsored well-defined social support system has made family the central focus of care networks where women play the primary caregiver's role. However, changing family structure with increasing nuclearization, women's education, and subsequent professional career, the available expensive private institutional care has thrown many challenges before the critical care system and pushes women with dementia more vulnerable in terms of their need for care and their dependent status in a patriarchal societal setup. Thus, it is necessary for us to address the preventive measures and affordable home-based care for the well-being of women who have dementia. Following the Geronto-Feminist theoretical perspectives and ethnographic method, the present paper focuses on the burden of care and affordable home-based care for older women with dementia. The research includes participant observation, case study, and in-depth interview (IDI) of experts from various fields (e.g., yoga, psychiatrist, nutrition, and ayurveda) as tools to propose an affordable care model.

**Keywords** Elderly women · Dementia · Yoga · Nutrition · Ayurveda · Psychiatrist

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## Introduction

The world population is gradually turning gray. The population aged 65 and above is growing faster than all other age groups. According to the World Population Prospects, the 2019 Revisions data shows that by 2050, one in six people in the world will be over age 65 (16%), up from one in eleven in 2019 (9%). By 2050, one in four persons living in Europe and Northern America could be aged 65 or over. In 2018, for the first time in history, persons aged 65 or above outnumbered children under five years of age globally (<https://www.un.org>). Since 1950, life expectancy has substantially increased in all regions due to breakthroughs in medical science and technology.

According to the State of World Population 2019 report by the United Nations Population Fund (UNFPA), India's population in 2019 stood at 1.36 billion, growing from 942.2 million in 1994. Six percent of India's population was of the age 65 and above.

India also recorded an improvement in life expectancy at birth, which was 47 years in 1969, growing to 60 years in 1994 and 69 years in 2019 (<https://economictimes.indiatimes.com>). As per the 2011 census, about 104 million elderly persons in India, 53 million are females, and 51 million are males (Government of India, 2016). For the last two decades, Indian females have outnumbered elderly males. This longer life span is leading to many other chronic illnesses, and one such is dementia.

Dementia is usually chronic, characterized by a progressive deterioration in intellect, including memory, learning, orientation, language, comprehension, and judgment due to disease of the brain. It mainly affects older people; in only about 2% of cases, the disease starts before the age of 65 years. It is also a degenerative disease and worsens with time (Shaji et al., 2010). The global prevalence of dementia as per the World Alzheimer's Report 2009 indicates that there were 35.6 million people with dementia by 2010. These numbers will double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Almost 58% of dementia-affected people will be living in low- and middle-income countries, which will rise 71% by 2050. In the next 20 years, it forecasts 40% increase in the number in Europe, 63% in North America, 77% in Southern Latin America, and 89% in developed Asia Pacific Countries. There will be 117% growth in East Asia, 107% in South Asia, 134–146% in the rest of Latin America, and 125% in North Africa and the Middle East (World Alzheimer's Report 2009). Dementia is a formidable public health challenge for many reasons, including high global prevalence and the economic impact of dementia on families, caregivers, and communities: the social stigma and subsequent social exclusion associated with the disease increase the burden. Therefore, the global health community must recognize the need for action and place dementia on the public health charter for action (WHO, 2012; Mukherjee, 2018).

Undoubtedly, the vulnerabilities of dementia patients are high. Still, it magnifies with poor, older women dementia patients who are trebly vulnerable by their class position, age, and gender along with the disease. Financial dependency and the status of primary caregivers inside the home often make women more vulnerable, especially when they require intensive care. Developed countries have put affordable geriatric care under their social securities extended by the state. Nevertheless, India's evident absence of required social security measures for the elderly turns the field of senior care extremely challenging (Mukherjee, 2015, 2018).

## **Methodological and Theoretical Background of the Study**

In this backdrop, the following study, by adopting the ethnographic method with the use of participant observation, case studies (20 dementia patients in home care and ten dementia patients in institutional care) and in-depth interviews (IDI) with experts try to assess the care burden of the disease and propose a non-clinical affordable care model for Indian dementia patients. The limitation of the study is its non-inclusive character in terms of the sample. In the absence of geriatric units in public hospitals, we had to depend on the private system to access patients diagnosed with dementia. Thus definitely, there is a class and urban bias in the sample. However, since we were aware of our limitations, we tried to overcome them in research.

In this study, we have tried to understand the core challenges posed by dementia through the "capability approach." When poor, marginalized women have dementia during old age, their dependence and subordination reach their nadir. They have been deprived of their full participation in society as they continue to be marginalized socially, economically, physically, and politically across the world. Martha Nussbaum, a capability theorist, has indicated that "unequal social and political circumstances give women unequal human capabilities" (Nussbaum, 2002: 1). Dementia is increasing the vulnerability of the lives of already vulnerable, like poor women (Mukherjee, 2018). A person's capability is the alternative opportunities available to her, the extent of her positive freedom. The valuation of her positive freedom is determined by her access to objective well-being based on the range of available options (Sen, 1993, p. 31). A person who has a disability may have a larger basket of primary goods and yet have fewer chances to lead an everyday life (or pursue her objectives) than a non-disabled person with a smaller basket of primary goods. Similarly, an older person or a person with dementia can be more disadvantaged in a generally accepted sense even with a larger bundle of primary goods (Sen, 1999: p. 74). Even if a person with a disability earns significantly, they might require an even more significant amount to accomplish the same functioning as other non-disabled people.

Gary L. Albrecht, Patrick J. Devliegerin's article "The disability paradox: high quality of life against all odds" (1999) defined the concept "**disability paradox**". The disability paradox highlights the importance of personal experience with disability in defining the self, view of the world, social context, and social relationships. Our interpretation of quality of life in terms of balance shares many of the assumptions and findings of Antonovsky's salutogenic orientation and the closely related theory of the sense of coherence Antonovsky (1987). Based on Antonovsky's work, we can understand how some people with disabilities establish and maintain a deep understanding of well-being and manage stress well. In contrast, for others, disability presents an enormous problem. Usually, women who have dementia do not experience a high quality of life because:

- They do not have ordered and predictable worlds.
- They do not possess the knowledge, resources, and social contacts that provide the social adhesiveness necessary to reconstruct a balance and well-being in their lives.
- Their low quality of life is often related to impairments that produce fatigue, constant or unpredictable pain, and physical and social environments that discourage them from becoming empowered and acting as agents in their own lives.
- The sociological evidence suggests, then, that low quality of life for persons with dementia is based on the difficulty to manage impairments, lack of knowledge and resources, and disabling environments (Mukherjee, 2018).

Therefore, theoretical initiatives to understand the quality of life among women with dementia demand those intervention efforts designed to enable and empower individuals and propose to build on both the organic base of impairments and the social model of disability. This paper is an effort to propose non-clinical affordable social care perspectives of the disease.

## Understanding Dementia

Dementia is described as a collection of symptoms, including the decline in memory, reasoning, communication skills, and a gradual loss of skills needed to carry out daily activities. The person with dementia also experiences changes in their mood or behavior and losses control of essential bodily functions. These symptoms are caused by structural and chemical changes in the brain due to physical diseases such as Alzheimer's disease. Like age, genetic background, medical history, and lifestyle, the factors can lead to dementia. Dementia is a progressive condition ([http://ard si.org](http://ard.si.org)). The changes are often small to start with, but the symptoms become more severe over time (<https://www.alzheimers.org>). Dementia is one of the significant causes of disability and dependency among older people worldwide, and it also

causes lots of stress and strain for their caregivers and families. It is the cumulative outcome of a lack of awareness, scant understanding of dementia as a disease, and barriers to access care and diagnosis. There are four major subtypes of dementia, and each subtype has its specific characteristics. The following are the subtypes of dementia (Shaji et al., 2010).

**Alzheimer's Disease:** Alzheimer's disease is the most common form of dementia. The symptoms occur when the brain is damaged. During the disease, proteins build up in the brain to form structures called plaques and tangles, leading to the loss of connections between nerve cells and eventually to the death of nerve cells and loss of brain tissue. It is due to the shortage of some brain chemicals in the brain (Shaji et al., 2010).

**Vascular Dementia:** It is the second most common type of dementia; it occurs when the blood flow reduces in the brain. Blood carries essential oxygen and nourishment to the brain. Without it, the brain cells can die. The network of blood vessels which carries blood around the body is called the vascular system. Stroke-related dementia takes place when there is the occurrence of a series of small strokes. It also includes dementia that occurs after the stroke is called post-stroke dementia (<https://www.alzheimers.org.uk>).

**Dementia with Lewy Bodies (DLB):** The proportion of Lewy bodies dementia is less than five percent. The early characteristic of Lewy bodies' dementia is marked by fluctuations in cognitive ability, visual hallucinations, and Parkinsonism (tremor and rigidity) (Shaji et al., 2010).

**Frontotemporal Dementia (FTD):** Frontotemporal dementia (FTD) refers to a group of diseases; the damages are seen in the brain's frontal or temporal lobes, which results in significant changes in personality, behavior, and language ability. The two frontal lobes of the right and left at the front of the brain are mood, social behavior, attention, judgment, planning, and self-control. Damage can lead to reduced intellectual abilities and changes in personality, emotion, and behavior (<https://www.fightdementia.org>).

Common symptoms experienced by people with dementia syndrome

Early stage	Middle stage	Later stage
<p>Friends and family generally overlook dementia early stage as a problem related to old age—just a normal part of the aging process</p> <ul style="list-style-type: none"> <li>• Patients become forgetful, especially regarding short memory</li> <li>• They have some difficulty with communication, like finding the right words</li> <li>• They feel lost in otherwise familiar places</li> <li>• They lose time tracking, including time of day, month, year, and season</li> <li>• They have difficulty making decisions: be it a complex household task or matter related to finance</li> </ul> <p>Patients may become less active and lose interest in activities and hobbies. Mood swings, including depression or anxiety, are expected. They may react unusually angrily or aggressively on occasion</p>	<p>With the gradual progression of the disease, limitations become more apparent and more restricting</p> <ul style="list-style-type: none"> <li>• Patients tend to become more forgetful, especially with short-term memory</li> <li>• They encounter increasing difficulty in comprehending time, date, place, and events and communication (speech and comprehension)</li> <li>• They become dependent on personal care (toileting, washing, dressing) and managing day-to-day life</li> <li>• Life becomes challenging as they can not live alone safely without considerable support</li> <li>• Behavioral changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things that do not exist). They often display inappropriate behavior in the home or the community (e.g., disinhibition, aggression)</li> </ul>	<p>The last stage is characterized by total dependence and inactivity. Memory disturbances become a grave concern, and the physical side of the disease becomes evident</p> <ul style="list-style-type: none"> <li>• Usually unaware of time and place, patients have difficulty in understanding what is happening around them</li> <li>• In this stage, patients become unable to recognize relatives, friends, and familiar objects and ultimately become dependent on others for self-care</li> <li>• Patients may have difficulty in swallowing and have bladder and bowel incontinence. They face change in mobility, may be unable to walk, or be confined to a wheelchair or bed</li> <li>• Behavior changes may escalate and include aggression toward the caregiver; nonverbal agitations (kicking, hitting, screaming, or moaning) are also part of the changed behavior</li> </ul>

Source WHO (2012, p. 7), World Alzheimer’s Report (2009), World Health Organization (2006), Mukherjee (2018)

## Understanding Dementia as Caregiver’s Challenge

As per the global burden disease report, dementia is the second most burdensome chronic non-communicable disease. There is a need for enormous care for older people who are suffering from dementia. Generally, the care is provided by the informal caregivers (family caregivers), which is unpaid. Almost 10 million Americans provide unpaid care for a person with one or the other forms of dementia. Among

the caregivers, the person who takes care of the dementia patient feels stressed with higher levels of psychological illness because of intensive and extensive care. The economic cost of dementia worldwide estimated in 2009 Alzheimer's report is US \$315 billion. The annual cost is estimated at US \$1521 in a low-income country. It is rising to US \$4588 in middle-income countries and US \$17,964 in high-income countries (Prince & Jackson, 2009). Dementia India Report 2010 estimated that the cost of taking care of a person with dementia is about 43,000 annually, much of which is met by the families as the state is virtually nonexistent in this sector. At present, the institutional cost in private clinics ranges from Rs. 30 000–40,000/pm, which is prohibitively high for ordinary citizens (The dementia India report, 2010, Mukherjee, 2018).

Treating dementia as a stigma, treating the individual as undesirable, emphasizing its symptoms is unhelpful. Professor Peter Piot says that overcoming stigma is the first step to beating Alzheimer's disease and dementia (Batsc et al., 2012). In the world's population, every 1 in 20 persons is dependent. Thirteen percent of older people who are aged 60 years and above are dependent. The global dependency will be changing drastically between 2010 and 2050; people worldwide will be nearly doubled from 349 to 613 million. The number of older people in need of care will be 101 to 277 million, increasing drastically in low- and middle-income countries. The need for long-term care for dementia-prone persons is very high in high-income countries. Due to this, there is a transition from home care to institutional care and nursing homes. The report says that half of the dementia patients need personal care support. About four-fifths of dementia patients need nursing home care (Prince et al., 2013).

### ***Social protection for older people with dementia in low- and middle-income countries***

Population-based catchment area	Number	Receiving a government or occupational pension (%)	Receiving a disability pension (%)	Receiving income from family transfers (%)	Experiencing food insecurity (%)	No children within 50 miles (%)
Cuba (urban)	323	81.4	0.9	7.4	5.6	19.5
Dominican Republic (urban)	242	27.3	0.8	23.6	13.7	25.1
Venezuela (urban)	146	41.1	4.1	2.7	2.7	13.4
Mexico (urban)	93	78.5	1.1	7.5	3.2	4.3
Mexico (rural)	87	34.5	2.3	17.2	12.6	5.8
China (urban)	84	84.5	0.0	11.9	0.0	0.0
China (rural)	56	10.7	0.0	23.2	3.6	7.8
India (urban)	75	13.3	2.7	28.0	28.0	5.3
India (rural)	108	26.9	0.0	44.4	17.6	10.9

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Population-based catchment area	Number	Receiving a government or occupational pension (%)	Receiving a disability pension (%)	Receiving income from family transfers (%)	Experiencing food insecurity (%)	No children within 50 miles (%)
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Source World Health Organization (2012), dementia: a public health priority, p. 43

In India, it is estimated that 3.7 million people are being affected by dementia in 2010. It is expected to be doubled by 2030. From the above table, it is clear that much of the care is met by the family members in India in the absence of a state-supported social security system. The future challenges stay as a financial burden. In India, this is the only report we can refer to for the information and details to know the impact of dementia in India. As per the report, there are 3.7 million Indians aged over 60 years who have dementia. Of these, 3.7 million, 2.1 million are women, and 1.5 million are men. It shows that the prevalence of dementia is seen more among women than in men. The report specifies that gender is not a risk factor for dementia (Shaji et al., 2010). In India, dementia remains a hidden problem due to a lack of awareness among the people, and they believe that it is a normal part of aging.

In India, persons with dementia continue to live with their families. Dementia care is usually a joint effort by the adult members of the family who stay in the same household. It is also expected that one person would be more involved with the care at any given point in time, and that person can be considered the primary caregiver. Most people with dementia lived with adult children and children-in-law. Living alone or with a spouse only was very uncommon. Carers were most often women and spouses, children, or children-in-law (Shaji et al., 2010).

## The Impact of Dementia Care

The caregivers' burden is multidimensional. It arises from physical, psychological, emotional, social, and financial stress associated with the caregiving experience. The caregiver's perception of the burden, rather than the perception of other family members, societal or healthcare providers, determines the impact on his or her life. The primary caregiver may be the spouse or partner of the person with dementia, or caregivers are often the son or daughter. Those who are financially capable hire professional caregivers. Different arrangements have different care challenges. A spouse often at the same age or older than the patient has health problems of his or her own, increasing the care challenges. Adult children are likely to be economically active and not prefer living with dementia patients or under professional/marital requirements live in faraway places. The families of younger people with dementia are likely to have additional sets of issues; they may have dependent children and financial commitments associated with younger age (Kitwood, 1997).



The very requirement of caregiving brings myriad restrictions in the caregiver’s life. They often give up full-time employment, switch to part-time jobs, give up employment, restrict time with friends and family, and sacrifice their pursuits and hobbies. Caring for a person with dementia is complex and demanding. Most of the time, the caregiver forced him/herself without any formal training. Caregivers generally report physical health problems and worsening of overall health. Carers of people with dementia are often at increased risk of psychological ill health due to all purposive stress associated with it (Brodaty & Donkin, 2009).

The negative consequences of caregiving have been widely studied. It is important to remember that most family and friends involved in providing informal care take pride in their role and perceive many positives. Caregivers’ perceptions of strain are often assessed using Zarit Burden Interview (ZBI); it has 22 items that assess the carer’s appraisal of the impact of their involvement in care (Prince et al., 2004). Among the 30 case studies conducted with dementia patients and their caregivers in both family and institutional setup selected, three cases are presented here. In contrast, significant findings from other cases are illustrated.

***Case studies of women dementia patients living with family members:***

**Case—1**

\*\*Original identity of the patient and caregiver is retained based on caregiver’s consent

Name of the patient	Name of the caregivers/relationship	Burden experienced by caregivers
Romila (aged above 90 years)	1. Rajeshwari (daughter) 2. Professional day care, Alzheimer’s Care Center	Little or no burden

**Background Information of the Patient:** Case 1 dealt with the dementia patient Romila (name changed), aged approximately 100 years. She was first diagnosed with symptoms of early dementia in the year 2013. She is a homemaker. Her husband served as a manager in the Bank of India. He passed away at the age of 81 years. Romila has been residing with one of her married daughters since the time her dementia was diagnosed. The help of a professional caregiver is taken from one of the Alzheimer’s centers in Bengaluru. Between 10 am and 4.30 pm, daycare center takes care of her from Monday to Saturday. Romila hails from Gujarat and has three sons and four daughters. All three sons stay in the USA. The elder daughter is bedridden and stays along with her husband in an old age home in Mumbai. The second daughter stays in California and the third one in New Jersey. The youngest daughter, Rajeshwari, alone takes care of her mother with occasional financial and emotional support from the siblings.

**Case History:** Rajeshwari is the primary caregiver in the family. Since Rajeshwari's husband Ashok got transferred to Bengaluru, the family had to shift to Bengaluru from Gujarat. Rajeshwari, along with her husband and mother, stays in Bengaluru now. Rajeshwari has one daughter who lives in the same apartment but in another block along with her husband. Rajeshwari's strength is her family, her husband, daughter, and son-in-law, who support her. They emotionally stood by her when she feels depressed and frustrated in her caregiver's role. Though she loves and cares for her mother very much, she suffers a lot from seeing her condition. Rajeshwari's daughter works in a private bank, and son-in-law, a graduate from IIM, works in Accenture. Sometimes she curses God and asks herself—*"why me,"* why everything happens to me, and why the entire burden has to be suffered by me. When Rajeshwari discusses her mother's condition and tantrums with her siblings, no one except her elder sister expresses willingness to share the burden of care. Rest all wanted to send their mother to institutional care. Rajeshwari said that her son-in-law is more supportive and helps her to overcome depression by his positive thoughts. He is more like a son than a son-in-law to her. She also quoted her son-in-law's word that—*"when you being daughter are not willing to look after your mother, how can you rely on old age home to look after your mother||well."* As such, he is the source of support and strength to Rajeshwari. As they live in the same apartment, they often visit home on weekends. Rajeshwari's son-in-law also spends time with Romila and joins them for bhajans on Sunday morning. Maids have been kept for cooking and other household cleaning purposes.

Another interesting matter is that Rajeshwari is fond of pets and has two dogs, and their presence makes her feel happy, working as a stress reliever. This routine continues every day. However, on Sunday, there is a change in their routine. It is a special day for Romila as she will be taken to Nagarjuna restaurant. It is so familiar that even the hotel management and workers are close to them. They visit the same restaurant every Sunday, and when they reach there, in no time, table arrangement will be made without making them wait for a long time.

**The behavior of the patient and engagement in a daily routine:** Romila does her work by herself like taking a bath, going to the toilet, wearing a saree, folding her clothes and bedspread, etc., but Rajeshwari makes sure that Romila's belongings will be kept in prescribed proper places and well maintained. Her day starts with taking a bath, doing Tulasi puja, and then having a cup of tea with biscuits. She comes to the dining table to have breakfast when her son-in-law (Ashok) calls her. She will have her breakfast along with him, whether breakfast/lunch/dinner, she takes a longer time (minimum 45 min) to complete it. After that, she will be eagerly looking out for the vehicle to go to the Alzheimer's daycare center. She seems to be happy going out there. The center will charge 16,000/- monthly to provide lunch, tea, biscuits, and a vehicle facility to pick up and drop.

Romila likes to have food (South Indian), especially sweets (Kesaribath in colloquial language) made of broken brown rice. Another unique thing about Romila is that she likes to wear new sarees. This shows her love for life. She likes to go around the city. On the other hand, according to the family members, she turns very aggressive on regular intervention. She does not seem to be in average condition. Seeing her in such a condition, neighbors who are ignorant about the problem make negative comments (spell of black magic, etc.), which increases the stress of caregivers who are family members.

Once when Rajeshwari took her mother to the movie theater, Romila started talking loudly with unusual behavior. She is not taken to cinemas, and even on television, she is not allowed to watch any of the programs except bhajans. This shows how even in an otherwise supportive environment, the caregiver is sufficiently stressed due to compromise of her social and personal life. At home, in order to keep her busy, Rajeshwari makes her mother do various activities like tying flowers for puja daily, cleaning up green leaves and vegetables. Sometimes she will be given a bowl of dal and pulses mixed and makes her separate them. These all activities improve her cognitive abilities. Sometimes, flowers will be put to her husband's photo frame by Romila. However, she does not remember who he is and thinks that it is God's photo. If she feels hungry, she does not tell directly but asks her daughter whether she drank tea. She does not remember anybody and calls Rajeshwari "Baa" (In Gujarati, mother).

#### **Major Findings:**

- **Care Model:**

- (a) In this case, a balance is maintained between the medical and personal care models, which recognizes and maintains personhood, uniqueness, and individuality. It acknowledges this in care plans and care pathways,
- (b) This professional care model respects autonomy, dignity, privacy, and the patient's rights as individuals and identifies strengths and positive aspects rather than weaknesses and problems (Slater, 2006, pp. 135–44),
- (c) Person-centered care has been promoted as the best practice in dementia care, but the concept is still poorly defined and lacks an empirical base (Brooker, 2003, pp. 215–222). A positive social environment is an utmost need in which the person living with dementia can experience relative well-being ([www.caresearch.com.au/caresearch](http://www.caresearch.com.au/caresearch), Mukherjee, 2018, pp. 67–70).

- **Caregiving**—In this case, there is a balance maintained between institutional care and homecare. The patient visits Alzheimer's center and is taken care of primarily by her daughter and other family members at home.

She has a very supportive grandson-in-law, and that shows caregiving is a gender-neutral activity.

- **Financial status**—The family is economically well off, and the patient has a regular income from fixed deposits. Therefore, they can afford institutional care (Rs. 16,000/pm). The family members did not express any financial burden in looking after the patient.
- **Significant symptoms observed**—The symptoms of the patient are unusual hallucinating behavior, forgetfulness, and memory loss.
- **Experience of burden**—As per the Zarit Burden Interview scale, the interpretation of the score of this family caregiver is **17**, and the interpretation of the score is **little or no burden**. When care is shared, or the caregiver receives physical (daycare center) and emotional support (some of the siblings and daughter and son-in-law), the stress of caring or care burden is significantly less.

## Case—2

\*\*\*Original identity of the patient and caregiver is retained based on caregiver's consent.

Name of the patient	Name of the caregivers/relationship	Burden experienced by caregivers
Eshwari (age 77 years)	1. Malthi Mohan (daughter-in-law)	Mild to moderate burden

**Background Information of the Patient:** Case 2 deals with a dementia patient named Eshwari, 77 years old, a widow living with her son and daughter-in-law. She has completed high school and lived her life as a housewife. Signs of dementia were witnessed in her 3–4 years back (2014). She receives the pension from her husband as a source of income.

**Case History:** Malthi Mohan, aged 51 years, has completed her postgraduation in social work (MSW). Currently, she is working as a welfare officer in Mathruchaya Trust in Sevashetra hospital. Malthi Mohan is a caregiver to her mother-in-law, taking care of her since she was diagnosed with dementia 3–4 years back. As Malthi Mohan is working, her care burden is shared by her family members, i.e., her husband and daughter. They are her source of strength and support. Malthi gives a hint to Eshwari as to recognize and remember people. Malthi's daughter Ankita goes to college, and if she does not arrive by 5.30 or 6.00 pm, Eshwari starts murmuring and asks Malthi why she has not come? This indicates that affection from family members makes her remember,

which will not be there in institutional care. Malthi's says that her mother-in-law and daughter both have bonded with each other, and Ankita loves and takes care of her grandma. Family members take Eshwari when they go for an outing, and Malthi says that she will not help her while getting down from the car as it may become a habit, and she may always depend on her for that. She remembers her family members but cannot remember or recognize others. As Malthi says, it embarrasses her sometimes, but the fact is that all her relatives know the condition of Eshwari. The family knew about dementia earlier itself as it was hereditary in their family. As Malthi was familiar with the dementia problem and its symptoms, she was not frustrated or irritated by her in-law's behavior. She could understand her age-related problems. Relatives and neighbors are very caring and helpful and spend time with Eshwari if she is alone at home. Malthi's presence at home and conversation with Eshwari make much difference. Eshwari is talkative; she wants someone to talk to and stay with her. They both have very close bonding and share household chores.

Malthi says that her professional career is not disturbed or affected while taking care of her mother-in-law. Her office is very near to the house, walkable distance. She leaves home at 9.00 am, and till 12.00, Eshwari is busy doing household work and gardening; meanwhile, the maidservant will come and be with Eshwari. At 1.30 pm, Malthi will come for lunch, and after 2.30, Eshwari will sleep for a while and read books. She feels bored for an hour when Eshwari's granddaughter comes home and spends time with her. Malthi says that it is not a financial burden for her as Eshwari gets a pension. She is given Ayurvedic medication, which is comparatively cheaper than English medicines. Malthi says that it is difficult for people who are financially weak as medical expenses are high nowadays.

**The patient's behaviors and engagement in daily routine:** Eshwari is physically fit; no institutional or professional caregiver is required. She is physically capable of doing work on her own. She is very talkative, talks continuously to everyone as they enter the home. Eshwari remembers and recognizes her family members, i.e., her son, daughter-in-law, and granddaughter, but not familiar with or recognizing other relatives. In order to keep her active, Malthi engages her in household work. Eshwari enjoys gardening, sowing seeds, cleaning pots, planting new ones, and household chores. Symptoms recognized by them were like forgetfulness, talking the same thing again and again, forgetting things to do like closing the tap after using it, could not recognize relatives and others who are not often met or seen by her, and Eshwari had a problem with hearing if anyone rings the bell.

**Major Findings:**

- **Care Model** followed, in this case, is the medical care model, personal care model, along with **the risk enablement and safeguarding model** as her daughter-in-law is a social worker herself. This model emphasizes

the development of systems for enabling and managing risk, which allows people with dementia to retain as much control over their lives as possible (Mukherjee 2015, 2018)

- (a) This model recognizes the strengths that each person with dementia possesses and builds on the abilities that he or she has retained.
  - (b) This approach takes a tailored approach for risk management by acknowledging that dementia affects different people in different ways.
  - (c) Acknowledgements that a shared agreement about risk will not always be possible, but a shared understanding of the viewpoints of all those who are affected by decisions is always possible.
  - (d) Therefore, this model helps in identifying less cumbersome alternatives for patients as well as caregivers.
  - (e) Strike a good balance between protecting patients while ensuring the quality of life for the caregivers by mitigating risk.
- **Caregiving**—The patient is cared for by family members; the primary caregiver is the daughter-in-law. The patient is physically active, walks herself, does the task in her daily routine. The caregiver feels mild to moderate burden due to dual role responsibilities.
  - **Financial status**—The family members did not express the financial burden of looking after the patient since the patient receives her husband’s pension as a source of income.
  - **Significant symptoms observed**—The patient’s symptoms are forgetfulness, talking the same thing repeatedly, forgetting things to do like closing the tap after using it, and cannot recognize relatives and others who are not often met or seen by her.
  - **Experience of burden**—As per the Zarit Burden Interview scale, the interpretation of the score of this family caregiver is **23**, and the interpretation of the score is **mild to moderate burden**.

**Case—3**

\*\*\*Original identity of the patient and caregiver is retained based on caregiver’s consent.

Name of the patient	Name of the caregivers/relationship	Burden experienced by caregivers
Leelavathi (age 89 years)	Shanthi G. (daughter-in-law)	Moderate to severe burden

**Background Information of the Patient:**

In this case, dementia borne Leelavathi is 89 years old, a homemaker, diagnosed with dementia in 2000. For the past 17 years, she has been looking after by her daughter-in-law Shanthi. Leelavathi has studied till high school. Leelavathi has three siblings, and she is the eldest among them. Since her childhood, she was most pampered among sisters. Father was key to her happiness and used to fulfill all her demands. When she was made to marry her husband (i.e., Shanthi's father-in-law), she was unwilling to marry him as he was not from an affluent background. Respecting her father's words, she finally agreed to marry. Even after so many years of married life, she was not happy for being married to him. However, opposite to this, her husband was very caring and fulfilled all her wishes. Leelavathi is a dominating personality and yielded lots of power within the family.

Nevertheless, an unfortunate horrifying incident took place. Leelavathi's husband committed suicide. It was a terrifying moment for the family members as there was no reason to die for it. There were no family disputes, quarreling between husband and wife, and any other problems. As such, it had a profound impact on the family members. It might be one of the reasons for Leelavathi's mental health problem. Leelavathi is financially independent as she receives her husband's pension.

**Case History:** The primary caregiver is a daughter-in-law, Shanthi, aged 57 years. Since Shanthi is a freelance social science researcher, she has given a detailed subjective account of her mother-in-law and experiences that she has undergone from a researcher's perspective. Leelavathi often shouts at Shanthi hysterically for no reason. Leelavathi even tried to blackmail Shanti by trying to falling into well. However, as Shanthi knew about her self-centered mother-in-law, she knew how to control her and told her to jump into well, and she would call her neighbors to lift her. However, from then on, Leelavathi never behaved like that. They closed the well in fear, but her tendency to scold Shanthi continues. Not only Shanthi, but also Bhagyamma (Bhagya) was a victim of her assault. Bhagya is a caregiver (assistant) to Leelavathi and looked after household chores. Leelavathi often uses abusive words that frustrate Shanthi, leading to disquiet between them as Shanthi has never been exposed to such words.

Initially, Shanthi was unaware of dementia and its symptoms. She used to get more frustrated. Shanthi observed many things. When Leelavathi was normal, she used to be finicky about personal hygiene, but with the onset of the disease, she even used to forget to take a bath even after going to the bathroom. This was discovered when Shanthi found lice were in her eyebrow, and with close observed Shanthi found many lice even in the pubic hair. She had gone entirely unhygienic. That was the time Shanthi thought of giving her medical treatment. When Shanthi revealed such behavior of Leelavathi to her sisters-in-law, no one believed her, although they were very close and friendly

with Shanthi. This incidence created more complexity and conflicts at home. Later everyone agreed to look after their mother, but they could not manage her even for a week. They felt sorry for Shanthi and trusted her words about their mother's behavior. One of the Leelavathi's daughters who stays in Mysore could not keep her mother for a long time. Her authoritarian personality has created some amount of unpleasantness at her daughter's place. The other two daughters of Leelavathi, who live in Mumbai and the USA, were unwilling to take care of their mother. Instead, they wanted to send her to a care home. Even Shanthi felt that the institutional care would be helpful for Leelavathi because she might be with the same age group, which may suit her positively.

Leelavathi behaved and pretended to be regular with everyone and liked being at home. She is very attached to the home. Shanthi noticed that the behavior of Leelavathi got worsened during the renovation of their house and that bothered everyone in the family. However, often it is seen that dementia patients relate better to their past. They have a concise memory of the present. The old house was associated with fond memories of Leelavathi's early life, and renovation of the said house was disturbing to her. Leelavathi never liked to go to any relative's home but instead wished her daughters, relatives to visit her home.

Shanthi says that because Leelavathi's authoritarian is cruel (from the beginning) personality, she is never attached to her emotionally. However, being human, it was her moral responsibility to take care of her. Thus, patients' past and present attributes have a lasting impression on the caregivers' minds and accordingly increase or decrease the burden of care.

For the last six months, they have appointed a professional caregiver to take care of her, and Shanthi's husband started involving in his mother's care only after his retirement. Leelavathi loves to cook, do puja, and light *diyas*. But because of her dementia, she often forgets to switch off the gas stove, resulting in a fire accident. Once while doing puja, her clothes caught up with fire. As a result, she was not allowed to work in the kitchen. Shanthi had to replace *diyas* with electric lamps to prevent future problems. This incident might have brought a kind of depression in Leelavathi. She is capable of doing her work and requires only a little assistance. Leelavathi is very independent-minded and prefers doing everything by herself. Initially, she was allowed to wash her plates, but she used to forget, clean them properly, and stop the water tap, resulting in a water drain, so she could not do any work. Her conservative caste taboo also prevents her from seeking the help of Bhagya—domestic help. Often she confuses her bed or living area as a toilet and soil space. Thus to avoid this, to keep her and the clean home diaper is being used for her. Gradually, her dependence on Shanti is increasing as often she forgets how to wear clothes (elaborate traditional Indian dressing makes it more cumbersome). Sometimes she even forgets how to chew or swallow food.

**Major Findings:**



**Care Model:** For Leelavathi, along with the medical and personal care model, the social care model was followed. The social care model emphasizes: **maximizing personal control, enabling choice, respecting dignity, preserving continuity (of lived experience and care provision), and promoting equity.**

- **Caregiving**—The primary caregiver is the daughter-in-law, whom her husband and professional caregivers accompany. The caregiving becomes stressful due to the authoritarian personality of the patient. The patient and primary caregiver's strained relationship led to the caregiver's stress and subsequent increase in hypothyroidism and high blood pressure. The burden of care has immensely impacted her quality of life, career, and health.
- **Financial status**—The family members did not express the financial burden of looking after the patient since they are economically well off, and further the patient is also financially independent.
- **Significant symptoms observed**—The symptoms of the patient noticed were strange behavior, assaulting with abusive words, unhygienic, forgetfulness.
- **Experience of burden**—As per the Zarit Burden Interview scale, the interpretation of the score of this family caregiver is **43**, and the interpretation of the score is **moderate to severe burden.**

## Findings on Family Caregivers

**30%** of the caregivers nearly always feel that they do not have enough time to attend other responsibilities; working and career-oriented women who are also caregivers and those look after two dementia patients feel more deprived of time for their things.

- **35%** of caregivers always have the feeling of anxiety between caring and other priorities. Caregivers who are women are expected to do much multitasking and caregiving responsibilities, leading to a high incidence of stress among caregivers.
- **85%** of the caregivers felt the burden of dependency; the height of dependency will increase with the progress of the disease.
- Only **10%** of the caregivers feel that their health has suffered due to caring responsibilities.
- **30%** of the caregivers quite frequently feel that they have disturbed social life. The personal space of an individual often goes missing.
- **5%** of the caregivers strongly felt embarrassed because of irrational behavior.
- **60%** of the caregiver feels that their demented relative nearly always expects/demands them to caretake.
- **75%** of family caregivers never felt financial pinch since most of the studied patients either are availing the pension or the family members have the steady source of income and are sharing the expenditure.

- 20% of family caregivers experienced little or no care burden because the patients are physically independent; when the family caregivers are supported by daycare center or professional caregivers, their physical and mental stress burden is significantly less.
- In total, out of 20 family caregivers, 12 family caregivers, i.e., **60%**, have experienced mild to moderate burden.
- The reason for all these 12 cases of dementia is the patient's increasing dependency and need for assistance on caregivers to manage their day-to-day activities.
- The 50% of patients in the family care have some income source as a family pension, rent from property, or fixed deposits. The other 50% of the dementia patients are dependent on others financially when the physical burden of care is added with the financial burden, the stress level increases.
- 15% of the family caregivers have 24 × 7 care services at home, and more than one person shares 40% of cases of significant care in the family. Although women are the primary caregivers, even men are also coming forward and joining hands in caregiving which is a welcoming trend.
- Only 5% of the family caregivers have experienced moderate to severe burdens. In such cases, most of the time, the caregiver is a working woman who has to balance her profession, family, and caregiving at the same time.
- 15% of family caregivers expressed the feeling of severe burden. In such cases, there is a double burden of care for the family caregiver as the women caregiver is taking care of two dementia patients at home without any support from other family members. Physically and financially, both ways, patients are dependent on the caregiver.
- Among the caregivers, 55% of them are working women, but only 36.36% are in full-time jobs. 36.36% of them are into the flexible job and change their profession for balancing the caregiving and continuing with their profession. The other 27.7% of the caregivers have quit their jobs to take care the dementia patient at home and 9.09% of the caregiver has opted for the job, to relax them or support the family financially. The challenges faced by working women due to their dual role responsibilities of balancing care and other familial and professional responsibilities.
- When care is shared, or the caregiver receives physical (daycare center) and emotional support (some of the siblings and daughter and son-in-law), the stress of caring or care burden is significantly less.
- Due to lack of support, the general personality of the patient and degree of physical and financial dependence positively contribute to increasing stress.
- When family members and professional caregiver share the care, the care burden is mild to moderate.
- The authoritarian personality of the patient increases caregivers burden from moderate to severe level.
- Complete physical and financial dependence of the patient and non-cooperation and hostility of other family members increases the primary caregiver's burden to a severe level.

- When the primary caregiver handles more than one patient, the care burden increases.
- When care is shared by all family members and love is associated with that, care becomes a burden-free work. Again daughters are proved to be a better care provider.
- When there are supportive neighbors, that significantly reduces the stress burden of the caregivers; therefore, a sensitized community can also act as care support.

## Findings from Institutional Case Studies

- Periodic visits (absence of regular monitoring) of family members led to negligence on the institution's part. Although the family was shelling out Rs. 750/- a day, the patient received inadequate care.
- Often family uses institutional care facilities to dump their loved ones. The loneliness and dejection also create a sense of insecurity among patients staying in institutional care.
- Often families cannot afford professional caregivers. In such cases, the absence of women in the house (like wife or sister) or the stormy relationship between mother-in-law and daughter-in-law makes caregiving difficult.
- The vulnerability of dementia patients is generally high due to progressive degeneration of the brain. Those who are having money and property even have to depend on others for their well-being. Thus for the poor and patients not having family members to care for, the community and state can play the role.
- When the patients are in institutional care, there is a visible lax on the family member's side. They equate care with expenditure and do not evaluate whether a patient is receiving quality care or not.
- In the majority of cases, be it at institutions or home, caregivers often are not adequately trained to deal with dementia patients, and as a result, they extend palliative care only, without introducing any stimulating activities to the brain to arrest the progression of dementia.

## Limitations in Personal Care

Kitwood (1997) has identified a **culture of care** that arises when there is a narrow view of dementia dominates. He termed this culture of care as malignant social psychology. It is important to emphasize that it can arise even where care staff behaves in ways that they believe to be kind and altruistic. According to Kitwood, the most critical elements of malignant social psychology include

1. **Imposition:** Forcing a person to do something overriding desire or denying the possibility that they may have a choice.

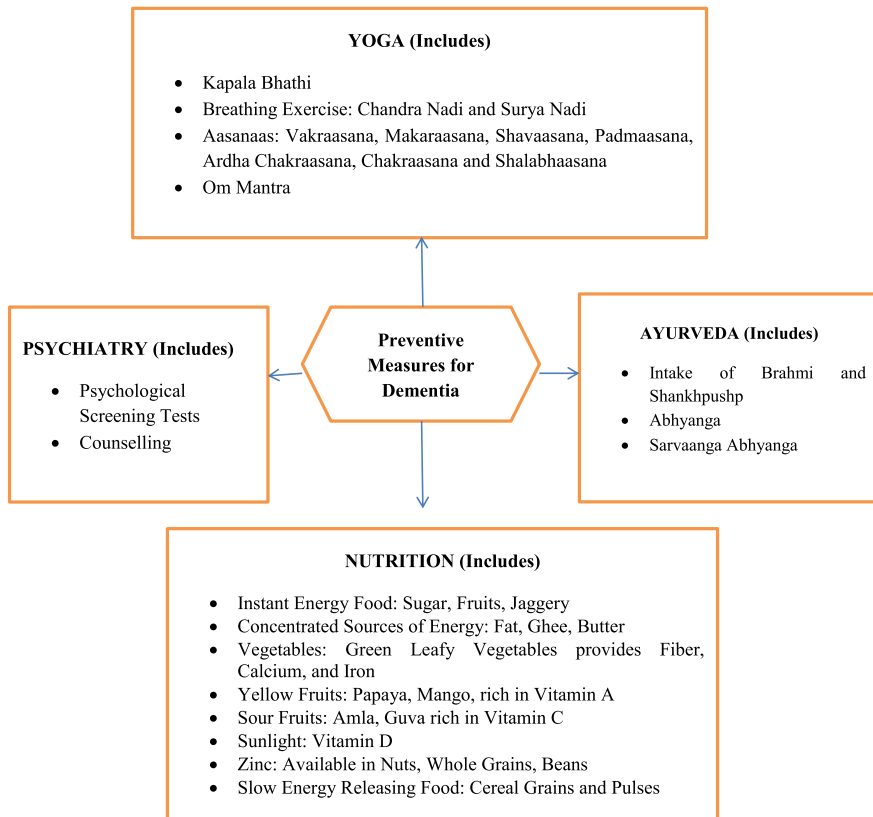
2. **Disempowerment:** Not allowing a person to use whatever abilities they may have.
3. **Infantilization**, i.e., treating an adult like a child; patronizing them.
4. **Intimidation:** Inducing fear through the use of threats, either explicitly or implicitly.
5. **Objectification:** Treating someone as if they were a piece of dead matter, an object to be moved, lifted without proper reference to the fact they are human beings.
6. **Banishment:** Sending a person away or excluding them, either physically or psychologically.
7. **Invalidation:** Fails to acknowledge the subjective reality of a person's experience and how they may feel.
8. **Withholding:** Refusing to meet the evident need or give asked for attention (Kitwood, 1997; Mukherjee, 2018).

## Issues in the Use of Antipsychotic Medication for People with Dementia

There has been an ongoing debate and increasing concern about antipsychotic drugs to manage behavioral and psychological symptoms in dementia. Across the globe, these drugs are used too often, and they are not free from potential risk. Studies indicate that prescribing antipsychotic medication for dementia varies from 20 to 33%. Undoubtedly, the first-line treatment for behavioral and psychological symptoms of dementia is non-pharmacological. Despite that, the prescription of psychotropic medication remains high. These drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia. The risks include cerebrovascular adverse events and mortality (Bannerjee, 2012; WHO, 2012). Evidence suggests that, in many cases, the challenging behavior of patients can be safely managed by the use of psychosocial interventions or a person-centered care approach. Antipsychotics should be considered an option only in imminent risk of harm to self and others. If these drugs must be used, they should be prescribed in low doses over short periods. (WHO, 2012).

Thus in the following section, we will be concentrating on a low-cost home-based social care system for healthy living for dementia patients in the Indian setup.

**Diagrammatical representation of preventive measures for dementia**



**Experiential analysis through expert advice: (Yoga, Ayurveda, Psychiatrist, Nutritionist/Dietician)**

**Yoga Expert:**

Dr. Hemant Bhargav. MBBS, MD (Yoga Rehabilitation) Working as Senior Scientific Officer, National Institute of Mental Health and Neurosciences (NIMHANS) Integrated Center for Yoga (NICY), at NIMHANS Campus, Bengaluru. He is working on yoga and mental health. According to him:

- After 45 years of age, human body starts degenerating speedily. One has to plan yoga activities with least stress postures. Blood circulation needs to be given emphasis in yoga activities, which are simple and easy to remember.
- Fast ones, Surya Namaskaaras, are to be avoided. Standing postures need to be lessened. More of sitting postures need to be adopted. Slower kapala bharathi of 20–30 per minute is preferred in aged participants, than in youths. Simplified pranayama, with inhaling from left and exhaling from right for three minutes and then repeating it vice versa, is easy for elders to remember and practice.

- Breathe in and out with ten rounds of straightened and stretched toes, loosen ankle joints, rotate ankle joints in clockwise and anticlockwise directions; loosen knee joints and hip joints. One shall relax after each exercise.
- After loosening of all joints, certain asanas need to be done up to ten counts, e.g, **vajra asana**. This is to be followed by **makaraasana** to be followed by **ahavaasana** (corpse pose for deep restoration). **kapaala bhathi** (skull shining) is to be practiced slowly for 20–40 rounds.

These activities/exercises help to maintain the brain active. The hippo temple volume is increased by yoga module in experiments at NIMHANS yoga that has protective action. A long-term comparative study of meditators and non-meditators revealed that cortex thickness has increased in meditators and yoga practitioners. Neuroplasticity, measured by brain-derived neurotrophic factor (BDNF) improved by meditation, which indicates better synaptic connections.

### **Ayurveda Expert:**

According to **Dr. Tejaswini BAMS, MD**, Research Officer, Advanced Center for Ayurveda NIMHANS by adopting shamana (cleansing or evacuatory), shodhana (body purification), and rasaayana (comprehensive package of medicines for healing) chikitsa krama's (treatment therapies) of Ayurveda immature aging can be prevented, along with the prevention of memory loss, hair loss, and skin deformation. Degradation or degeneration of organs as in dementia can be prevented by rasaayana chikitsa krama. Memory enhancement can be had by treatment with brahmi, shankh pushp (*Clitoria ternatea*), intake of milk will supplement calcium, while that of ghee with hot dishes/hot water helps in digestion. These ayurvedic treatments will lead to prevention of degeneration of nerves and improvement of skin too. Daily abhyanga will stimulate nerves. Application of brahmi oil can reduce sleeplessness. Whole body treatment (sarvaanga abhyanga) will facilitate general health improvement and reduce probabilities of dementia.

### **Psychiatry Expert:**

**Dr. C. R. Chandrasekhar**, Retired Senior Professor from NIMHANS, worked in NIMHANS for 34 years and retired in 2013. Presently, working in SAMAAD-HAANA, free counseling, and training center, for the last 11 years. Psychological tests and tools can be used to detect dementia as early as possible. Psychological screening or questionnaire can be used to check vocabulary, language ability, and communication skills to assess the situation. The individual can handle situation (like banking, going out) independently and dementia can be identified. The person, accordingly, can be referred to a psychiatrist or a psychologist. Taking care of demented persons is a challenge, as it affects ones' activities. They can get depressed or problematic. The neighbors or NGOs can help the primary caregivers. Following simple therapies can be suggested:

**Music therapy:** Playing music or singing a song as per the likings of the dementia patients; **cognitive stimulation therapy:** By using art and crafts for making painting and knitting, by doing daily activities like cleaning around the house by sweeping, wiping the table, or folding clothes and other household tasks to make the person feel a sense of accomplishment. Reading the newspaper, cooking or baking simple recipes together, working on puzzles, watching family videos, looking at books the person used to enjoy, attending the garden work, or visiting a botanical garden can be used as therapies.

The demented persons can be taken to rehabilitation centers, once in a month. The primary caregivers or their families can form social support groups and share their tasks in inevitable situations. With increasing nuclearization of families, women's dual responsibilities along with burden of care make it inevitable for seeking the help of the counselors to ensure better life for the demented families. Active people are less prone to develop dementia. So, staying active will help to avoid dementia. Environmental pollution also may cause dementia. The progress dementia becomes faster if a person experiences stress and anxiety. In vascular dementia, better management of diabetes may slow down the progress of dementia. In the participation in discussion, learning new things will help to postpone dementia. Home care is the best. Efforts should be made to make patient independent and active.

Government can help by opening good daycare/rehabilitation centers, especially for the elders. Organization of entertainment and recreation like activities in daycare center will help to keep the demented active. Any one above 50 years of age need to be screened for dementia at taluka, district level both in public and private hospitals.

### **Nutritionists Advice:**

Dr. Nirmala Yenagi, Retired Professor, Department of Food Science and Nutrition, Rural Home Science College, Dharwad. According to her, food helps in three ways. It provides energy, helps in growth, development and maintenance of body, and it repairs the body. The main components of food are carbohydrates, fats, and proteins. Instant energy foods are sugar, fruits, and jaggery. Concentrated sources of energy are fat, ghee, and butter. Slow energy releasing foods are whole cereal grains and pulses. Among fruits and vegetables, green leafy vegetables provide fiber, calcium, iron and carotene, yellow fruits, and vegetables, namely papaya and mango are rich in vitamin A, and sour fruits, namely amla and guava (also sprouted gains) are rich in vitamin C (which is also essential). These are protective foods and help maintain health generally.

All nutrients are essential for the body. Elderly people, as are less active, require less of carbohydrates. For elderly people, carbohydrates need to be in compound form as they release sugars slowly. This will help to maintain optimum level of blood sugar. Calcium is needed for strengthening of bones and muscle contraction. Quality protein is a must, for this we need to have milk in daily diet, along with cereals and pulses. Fruits rich in mono and polyunsaturated fatty acids are essential to maintain health with diabetic, hypertension, and cardiovascular problems. Sunlight

is a good source of vitamin D. Olive oil and cad lever oils are also source of vitamins. Zinc is also needed for elderly people as it helps in carbohydrate metabolism, sense, smell, and taste, also in secretion of insulin. Zinc is available in nuts, whole grain, and beans. Vitamin B12 helps in the maintenance of microflora in small intestine. It is needed for blood formation and maintenance of nervous system. Fiber helps in maintaining integrity of gastrointestinal tract. Fiber avoids constipation and reduces body weight and cholesterol. Diet schedule of elderly people should have breakfast, lunch, and dinner, duly balanced with energy, protective, and protein food. Diet should have more fiber and raw salad to maintain blood sugar and cholesterol levels. Early breakfast and early dinner are must for maintaining good health. Cooked food should be served as boiled or steamed.

## **Comprehensive and Affordable Dementia Care Model**

This affordable and economic care model is built with the idea that assisted family care is most suitable for the dementia patients as well as for caregivers. Assistance can come from professionals or from other family members. This care model exhibits how support in terms of care can be extended to the patients who are at different stages of dementia. This model also elaborates the role of the community and state in the process of affordable dementia care. Ultimate goal of this model is to provide dignified assisted living to the women elderlies whose physical dependence is multiplied with financial dependence.

### **Stage—1:**

- In the first stage, the family can support the elderly through regular periodic health checkup to diagnose the disease; the family members should try to understand that dementia as a disease. The family members should use the wrist bands or identity card for the demented patient once the disease is diagnosed as it will help them to be traced once they lost their way back home. They must save family members contact in fast dial option of mobile phones. Phones should not be password protected.
- The community can support the demented patients as well as the caregivers through creating awareness and social support. They must treat the patients with empathy. Community can play vigilant role in reporting abuse of dementive elderlies at the hand of family members.
- The state can contribute by providing mandatory-free dementia screening after 50+ at public hospitals, and government must open geriatric ward in the public hospitals and must organize the awareness campaign and free counseling facilities.



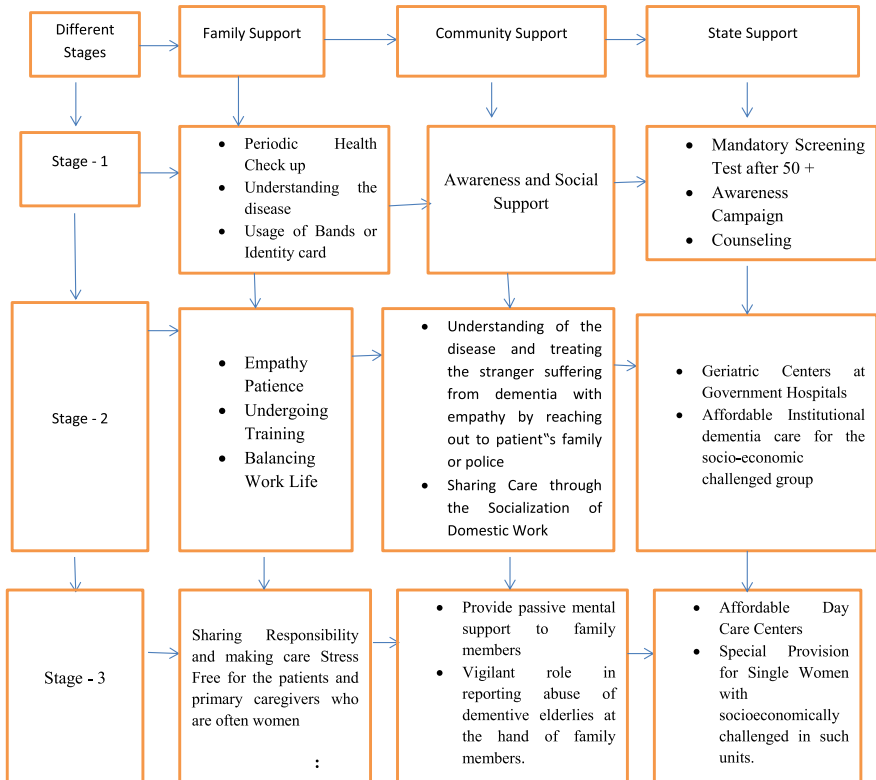
**Stage—2:**

- In the second stage, the dependence of dementive patients increases so does the care needs. At this level, caring must be shared among family members to give adequate rest to the primary caregiver. The family members (specially the primary caregivers) should undergo training on how to cope up with the situation. The family can support their demented relative with empathy like sharing the feelings and reacting to it positively.
- The community should understand the disease and treat the stranger suffering from dementia with empathy by reaching out to patient's family or police. The community can support through sharing care through the socialization of domestic work. This can help women caregivers to grow as a self-entrepreneur in the care service sector.
- The state should equip itself with good geriatric centers at government hospitals. The state should allocate with affordable institutional care for those who are socially and economically vulnerable.

**Stage—3:**

- Third stage is high dependence stage,, and therefore, the care demand is also very high. Sometimes family members can take external care help to distress themselves. But of course not everybody can afford that. In such cases, family can support by sharing responsibilities and making care stress free for the primary caregivers who are often women.
- The community can provide passive mental support to family members in this stage. Since patient is almost homebound with high dependence, community has limited role to play. Community can play vigilant role in reporting abuse of dementive elderlies at the hand of family members.
- As the care demand is very high at this stage, many a time family (where patient is a single woman, or caregiver spouse is very old, or nobody willing to share care burden) are not there to care, there we need state should be able to provide affordable institutional care with special provision for single women, socioeconomically challenged women in such units.

***Comprehensive and affordable dementia care model:***



## Toward a Geriatric Inclusive and Dementia Friendly Social Order

### Expected Role of Caregivers:

1. Institutional training is needed to equip them for better understanding of the disease, behavior of the patient, and deliver quality caregiving.
2. Opportunities to lessen the burden of stress of caregiving and induce enthusiasm to revitalize quality caregiving.
3. Extending family care facilities for the professional caregivers to improve their involvement in their task.

### Expected Role of Patients:

1. Timely and quality diagnosis should be provided to elderly or dementia patients in particular through compulsory dementia test after 50 years.
2. The family caregivers or the professional caregivers should engage the patients through mental stimulating activities in the early stage.

3. Making institutional care an affordable one for all.

### **Expected Role of Community:**

The integration of health and social care provides an opportunity to create a structured, coordinated, and strategic approach to community support for people with dementia and their caregivers to ensure their dignified stay in the community for long. According to Lindsay Kinnaird, the eight pillars of community support for dementia incorporate (Kinnaird, 2012, pp. 13–15; Mukherjee, 2018).

1. **Dementia practice coordinator:** A skilled practitioner who will regularly lead the care, treatment, and support for the patient and their caregivers. The same person should be coordinating access to all the pillars of support and ensuring effective intervention across health and social care.
2. **Therapeutic interventions:** To tackle symptoms of the illness—dementia-specific therapies to delay deterioration, enhance coping, maximize independence, improve quality of life, and need to be introduced in a trained fashion.
3. **Support for caregivers:** A proactive approach in supporting people in the caring role and maintaining the caregivers' health and well-being through community intervention.
4. **Personalized support:** Community must promote flexible and person-centered services to increase participation and independence.
5. **Community connections:** There is a need for support to maintain and develop social networks and benefit from peer support for both the person with dementia and the caregivers.
6. **Environment:** Building accessible public places following universal structures and through adaptations, aids, design changes, and assistive technology, there is a need to sensitize the community to maintain the person's independence and assist the carer.
7. **Mental health care and treatment:** Recognition and access to psychiatric and psychological services to maintain mental health and well-being for both patient and caregivers.
8. **General health care and treatment:** Availability of regular and thorough review to maintain general well-being and physical health is also a requirement.

### **Expected Role of Government:**

1. Policy prioritization to geriatric issues with required budgetary allotment and mandatory dementia screening for all citizen after attaining 60 years as prevention is easier than cure.
2. Provision for state run affordable geriatric daycare and institutional care services with trained caregivers accessible to all. Need of geriatric care centers and the counseling centers at the public/government hospitals equipped to look into the issues-related dementia and psychogeriatric care services.

3. Creation of awareness at the national level, state level, and at the local level about the elderly issues. Government support and funding for policy execution and research in the field of dementia.
4. Initiate measures to prevent degradation of environment and create awareness among the people regarding the problem of dementia through print and visual media.
5. There should be a private and public partnership in providing facilities to reach the larger number of people in facilitating and providing domiciliary care services.

## References

### *Books and Journals*

- Albrecht, G. L., & Devlieger, P. (1999). *The disability paradox: High quality of life against all odds*. Social Science & Medicine.
- Amartya, S. (1999). *Development as freedom*. Oxford University Press.
- Antonovsky, A. (1987). *Unraveling the mystery of health*. Jossey-Bass.
- Brodady, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217–228.
- Kitwood, T. (1997). *Dementia Reconsidered*. Buckingham: open University Press.
- Kinnaird, L. (2012). Alzheimers Scotland. Action on Dementia (pp. 13–15).
- Mukherjee, S. (2015). Caring elderly people suffering from dementia: A sociological analysis of various care models. In S. Jain, M. Wadhwa, N. Dabas & N. Rathi (Eds.), *Issues and concerns of elderly people in India*. Book Age Publications.
- Mukherjee, S. (2018). Dementia: A Capability Deprivation for Elderly Women in India. In P. Rekha & T. Van der Weide (Eds.), *Handbook of research on multicultural perspectives on gender and aging* (pp. 65–70). IGI Global.
- Nussbaum, M. (2002). Capabilities and social justice, international studies review. In *International relations and the new inequality* (Vol. 4, No. 2, pp. 123–135).
- Sen, A. (1993). Capability and well-being. In M. Nussbaum & A. Sen (Eds.), *The quality of life* (pp. 30–53). Clarendon.

### *Reports*

- Alzheimer's Disease International World Alzheimer Report. (2009). Editors Prof Martin Prince, Institute of Psychiatry, King's College London (chapter 1–2) Mr Jim Jackson (chapter 3–4) Scientific Group, Institute of Psychiatry, King's College London.
- Banerjee, S. (2012). The use of antipsychotic medications for people with dementia. A report for the Minister of State for Care Services (<http://www.nhs.uk/news/2009/10October/Pages/Antipsychotic-use-in-dementia.aspx>). Accessed 5 February 2012).
- Batsc, N. L., et al. (2012). *World Alzheimer's Report 2012: Overcoming the stigma of dementia*. Retrieved from [http://www.alz.org/documents\\_custom/world\\_report\\_2012\\_final.pdf](http://www.alz.org/documents_custom/world_report_2012_final.pdf). Retrieved on 13/5/2016

- Dementia UK, the Full Report. (2007). Alzheimer's Society: Dementia care and research. Kings College London. A company limited by guarantee and registered in England no. 2115499. Retrieved from <http://ardsi.org/downloads/main%20report.pdf>. Retrieved on 15/6/2016.
- Elderly in India. (2016). Published by Central Statistics Office, Ministry of Statistics and Programme Implementation, Government of India. Retrieved from [http://mospi.nic.in/sites/default/files/publication\\_reports/ElderlyinIndia\\_2016.pdf](http://mospi.nic.in/sites/default/files/publication_reports/ElderlyinIndia_2016.pdf). Retrieved on 28/6/2017.
- Elderly in India: Profile and Programmes (2016) Central Statistics Office, Ministry of Statistics and Programme Implementation, Government of India. [www.mospi.gov.in](http://www.mospi.gov.in)
- Kinnaird, L. (2012). Alzheimer Scotland, Action on Dementia (pp. 13–15).
- Prince, M., Bryce, R., & Ferri, C. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention*. Institute of Psychiatry, King's College London, UK Published by Alzheimer's disease International (ADI), September 2011.
- Prince, M., & Jackson, J. (2009). *World Alzheimer's Report 2009*, Institute of Psychiatry, King's College London, UK Published by Alzheimer's disease International (ADI). Heimer's Report 2009 Institute of Psychiatry, King's College London, UK Published by Alzheimer's disease International (ADI). Retrieved from <https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf>. Retrieved on 16/1/2014.
- Prince, M., Prina, M., Guerchet, M. (2013). *Alzheimer's disease international: World Alzheimer's Report 2013, Journey of Caring An analysis of long term care for dementia*. Published by Alzheimer's Disease International (ADI), London. September 2013. Copyright © Alzheimer's Disease International.
- Prince, M., Wimo, A., Guerchet, M. M., Ali, G. C., Wu, Y. T., & Prina, M. (2015). *World Alzheimer's Report 2015—The global impact of dementia, an analysis of prevalence, incidence, cost and trends*. Published by Alzheimer's disease International (ADI), London. August 2015. Retrieved from <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>. Retrieved on 19/8/2015.
- Shaji, K. S., Jotheeswaran, A. T., Girish, N., Bharath, S., Dias, A., Pattabiraman, M., & Varghese, M. (2010). *The Dementia India Report 2010: Prevalence, impact, costs, and services of dementia*. Alzheimer's and Related Disorders Society of India.
- Wimo, A., & Prince, M. (2010). *World Alzheimer Report 2010: The global economic impact of dementia. Introduction, methods, results and discussion* (unpublished). Retrieved from <https://www.alz.co.uk/research/files/WorldAlzheimerReport2010.pdf>. Retrieved on 5/9/2014.
- World Health Organisation. (2012). *Dementia: A public health priority*.

## Websites

- <https://www.un.org/en/sections/issues-depth/ageing/>. Retrieved date 7/10/2019.
- <https://economicstimes.indiatimes.com>. Retrieved dated on 7/10/2019.
- [https://www.alzheimers.org.uk/info/20007/types\\_of\\_dementia/2/alzheimersdisease](https://www.alzheimers.org.uk/info/20007/types_of_dementia/2/alzheimersdisease). Retrieved on 25/6/2017.
- [https://www.fightdementia.org.au/files/helpsheets/HelpsheetAboutDementia17-FrontotemporalDementia\\_english.pdf](https://www.fightdementia.org.au/files/helpsheets/HelpsheetAboutDementia17-FrontotemporalDementia_english.pdf). Retrieved on 27/6/2017.