

# **Dementia Home Care: Context and Challenges in India**

by Swapna Kishore\*

Family caregivers of persons with dementia (India) cope with extremely stressful situations and need support from people and systems around them. This note provides an introduction to dementia home care in India, a country where awareness is low, dementia is often confused with old age, diagnosis is delayed, support systems are pathetic, and where the society expects a lot from caregivers under the umbrella of duty, love, joint family, and culture, but does not know enough about dementia to effectively support families in such care.

Given the poor awareness and delayed diagnosis, families become caregivers before receiving any diagnosis; caregivers don't know that the patient's difficult behaviour is caused by a medical condition, and are not aware of appropriate techniques to handle the situation.

Poor knowledge about dementia means that much of the behaviour caused by dementia is seen as intentional and hurtful, and family members feel betrayed and bewildered, and often respond in ways that worsen the situation. Even professionals like surgeons and doctors prefer not to treat their own family members, and they acknowledge that it is difficult to remain dispassionate and objective when dealing with persons one is emotionally close to. Family caregivers (uninformed about dementia's impact on behaviour) are often upset or disheartened by the accusations flung by deluded patients, or when loved ones lose their memories and fail to recognize them.

Family members are thrust into the caregiver role because they need to do it. It is not their chosen vocation, nor are they trained for it. They squeeze the time, energy and money needed for this role along with other, equally important roles, like being parents, spouse, handling other elders and ailing persons, along with their own careers. Balancing multiple roles takes a toll on the entire family. Children may require support because they are preparing for important exams. They may require attention because they are being influenced by undesirable friends. A family member may fall ill, say, get cancer or a heart attack, or be injured in an accident. Because all these have to be handled along with care of a person with dementia, life is an endless struggle to fit in everything. Even a day's break is often infeasible. Dementia care is not a short-term adjustment of a few weeks or months--it extends for years.

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Because caregiving requires time and energy, caregivers often give up jobs or switch to part-time work (thus giving up income sources) while spending more money in care (increasing expenses). Every adjustment required for the comfort and care of the patient costs time and money, which means sacrificing something else, like foregoing tuition for a child, or a medical check-up for another family member, or reducing nutritious food. But many caregivers, feeling a sense of shame, do not talk of their financial problems.

Dementia awareness is very poor in India. People often criticize families based on deluded complaints of patients, or because of their own ideas of what care should be---this is based on what normal elders want, though it may be unsuitable for someone suffering from dementia. For example, relatives and neighbours may call family members cruel if they keep doors locked to prevent wandering. Or they may insist that families show "respect" for the patient by letting the patients take major financial and other decisions that they are no longer capable of making. Criticism sometimes reaches extremes like accusations of neglect or theft or attempted murder and people even threaten to inform the police. Caregivers have to cope with these in addition to trying to care for the patient.

The emotional cost of caregiving is particularly severe on close family members, because they feel involved with the patient. Seeing someone you love lose their memories is stressful, especially when the patient stops recognizing family members. Seeing them become increasingly dependent is also very distressing. And knowing that there is no cure makes it worse. Many caregivers who are blood-relatives of the patient have the additional stress that they too are at risk of developing dementia. As caregiving for the patient extends across years, sometimes more than a decade, all these combine to create a continued high-stress situation. Caregiving also occupies so much time and energy that the death of the patient leaves an unbearable vacuum and results in a loss of identity for the caregiver.

India's cultural environment equates care of dementia patients with the "joint family" system where people live with ageing elders. Caregivers are often bombarded with lectures on how they must "love" their parents, how elder care is "normal" and "duty", and how it is part of being "grateful" to parents. People are always advising them on what more should be done for the ailing parent, and get upset when their advice is not followed. Caregivers hesitate to mention their fatigue, sense of overwhelm, or financial difficulties in such an environment. Caregivers spend years of intense sacrifices in the relentless caregiving that a person with dementia requires; this is accompanied with extreme isolation as they spend more and more time providing care and cannot talk about their own burnout without hearing lectures on love and duty. Even for the lucky few who are in supportive environments, advice given by others is not always appropriate because very few people try to understand what would really help before offering advice.

Volunteers and other professionals are not always tuned to the realities of dementia home care. The solutions applicable in an institutional care environment are not directly transferable to a home care environment.

For example, it is often expensive (and even infeasible) to modify homes and make them suitable for patients. Having a full-time attendant in an apartment, sharing kitchen and toilets, is difficult to adjust to, and privacy is affected. There are security risks too.

Another example: In an institutional care setting, a team of professionals provides a collection of diverse skills to cater to the needs of the patients--the dietician, the physiotherapist, the occupational therapist, the cook, the attendant, the psychiatrist, and the volunteer who comes for "activities". At home, all this work is handled by the primary caregiver and a few others, all untrained, and all doing this in addition to multiple other roles. Yet these required skills are not instinctive, otherwise the "professionals" would not need years of training, observation, supervision and practice.

Being relaxed and calm while coping with a person with dementia is easier in institutional care, where handling a patient is part of a well-defined job. The home care setting is different; here, the caregiver is often sleep-backlogged and also emotionally stressed by seeing a loved one's strange behaviour. It is inhuman to expect a family caregiver to always be patient in such a case. Also, family caregivers do not always have the time. For example, a family caregiver who has to leave the patient at a day care and then go for an important meeting is likely to get restless if the patient is just not cooperating to get ready. The aspect of juggling multiple roles is often missed out by persons who only consider one aspect of the caregiver's life--the role in dementia care--and forget all other things this person is balancing all the time. A volunteer can take a day off for a personal emergency, but a family caregiver juggles other emergencies with dementia care. Even if unwell, the family caregiver still has to do what is needed for the patient at home. This is tremendously taxing physically and emotionally.

Dementia home care has been likened to a 36-hour day, and what is remarkable is that in spite of all these problems, most families adjust their lives and provide reasonable care for the patients. Yet family caregivers clearly need help. This note is an attempt to provide a flavour of home care realities so that concerned persons can provide suitable help and suggestions, while remaining sensitive and respectful of what families achieve in face of so many challenges.

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