

## DEMYSTIFYING DEMENTIA

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As the world observes World Alzheimer's Month in September, experts call for understanding the specific care that dementia patients need and how to prevent it

While conversations on mental health have entered mainstream discourse in India now, there's a fuzziness of perception that still surrounds the disease of dementia. Vague associations with 'memory loss', 'senility' and Alzheimer's have clouded the true nature of this illness in popular understanding, and its impact on the patient and the caregivers is often confused with the regular ravages of old age and geriatric care. The lens through which dementia is viewed needs sharper focus, as its incidence across the globe is likely to double every 20 years, with developing countries like India accounting for the maximum number of cases.

### Understanding dementia

For a disease that has still not found cure, and which continues to attract stigma, awareness can go a long way in equipping us to deal with it better. "Dementia is a general term for a group of brain degenerative diseases that cause forgetfulness, and behavioural and personality changes in a geriatric patient," says psychiatrist **Dr Amar Shinde** of Jagruti Rehabilitation Centre, which is conducting a Dementia Awareness programme in the city. "There's vascular dementia, frontotemporal dementia, but Alzheimer's disease is known to be responsible for almost 70–80% cases of dementia. Unfortunately, there's no treatment for Alzheimer's, but early detection through MRI brain scan and MMSE (mini mental state exam), neuropsychiatric evaluation will help slow down further degradation," he adds.

As the ageing population in India increases, the prevalence of dementia has increased too. Forgetfulness in old age is common and the symptoms of geriatric decline and dementia may overlap, but there are some tell-tale signs that should be watched out for. "In age-related memory loss, the person is able to function with minimal cognitive decline. If it's non-progressive, it's normal. But if it increases over time, usually when the person is above 60 years of age, it may be Alzheimer's," says city-based neurologist **Dr Hemant Sant**. While the exact cause of neurodegeneration is not known, Dr Sant observes that memory deficit may begin as early as around 30–35 years of age only to manifest into dementia later. Prevention becomes an important component in the fight against dementia.

### What can't be treated can be prevented

"Use it or lose it," is Dr Sant's simple mantra for keeping the brain active and in good health. The brain needs stimulation and new learning in order to function well. "Problem-solving, puzzles, hobbies, conversations, social interaction, especially for the post-retirement population, is very important for brain health. Using the brain as much as possible is key," he says. But it's not just senior citizens who should take note; prevention should start from as early as the 40s itself. "People start working on their brains only after the symptoms set in. But it's of little help when done post facto. Younger people who

are busy working and earning, who are stuck in the monotony of life, need to start using their brains in different directions. Keeping risk factors such as smoking, blood pressure, diabetes under control is also important,” Dr Sant advises.

**Mangala Joglekar**, a social worker currently pursuing her PhD on dementia and who runs the Memory Clinic at Deenanath Mangeshkar Hospital as a part of the neurology department, also offers memory improvement programmes for persons above 40 years of age, among other initiatives. “A stressful lifestyle, loss of sleep, tensions are commonly faced by the younger population today. The brain is really the epicentre of good health and yet, it is not talked about enough. There is a need to emphasise the role of the brain and the importance on working on it,” Joglekar informs.

When the disease strikes, there’s very little that can be done, except managing or stabilising it. Medicines, Dr Sant says, are effective only in the early stages of dementia. As the disease progresses, the role of caregivers and the non-medical aspects of disease management assumes greater importance. At the Memory Clinic, Joglekar says, her objective is to help improve the quality of life for both patients and caregivers.

### **Beyond medicines**

The non-medical aspect of dementia cannot be overstated, as the disease affects the mind, body, behaviour of the person and impacts the family in a huge way, believes Joglekar. While the patient struggles with his own degenerating condition, battling anxiety, depression, lack of interest, a disconnect with the world, the caregiver’s responses may range from denial, devastation, frustration, guilt, anger outbursts, even abuse of the patient. “The caregiver faces numerous challenges dealing with the patient. Often, they are not able to understand that the patient isn’t deliberately acting the way they are. Then there is extreme emotional and physical exhaustion, burn out, guilt caring for the patient. It’s a very stressful situation for the family,” says Rony George, director, Chaitanya Institute for Mental Health and secretary general, Alzheimer’s and Related Disorders Society of India (ARDSI), Pune chapter.

There is a need for more sensitised, trained care workers for dementia patients who respect them and are with them. “You may have doctors, nurses, but they cannot give 24x7 care. The ARDSI’s Pune chapter will soon come up with training programs for such care workers,” says George. It is important to strike the right mix of giving help and encouraging the patient to be independent, says Joglekar. So caregiver training, monthly support groups, memory lab that gives patients an opportunity to engage in various activities and caregivers a chance to bond with other caregivers are also on the offer at Memory Clinic. “The approach to patients has evolved over the years — from isolating them to offering person-centered care — the caregivers’ burden needs to be addressed too. The primary caregiver should be encouraged to lead a normal life, with a few hours to themselves, and the whole family should be encouraged to work together as a team,” Joglekar says.

BR Joshi, 83, who has been successfully managing his wife’s condition ever since she was diagnosed with dementia four years back, agrees. He, along with his son and daughter and some institutional help, has been able to adopt a healthy approach to the illness and its care. “There’s no use panicking when a loved one is diagnosed with dementia. You need to keep your balance, and accept the facts. Regular

meeting with doctors and medication help, and so does keeping the faith without going for irrational ways of treatment,” he says. Meanwhile, Joglekar hopes for a future where memory clubs for the elderly, like laughter clubs, become a common sight in our neighbourhoods.

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