

Chapter 2

Living with Failing Memory: A Caregiver's Perspective



2.1 Lack of Acceptance in Early Stage of Dementia

“I can’t think of life where my eyes could see, but wouldn’t comprehend, my legs are fine but my brain does not send the right signal to walk briskly, all my life’s creativity, intelligence, dignity and respect has converted to living at the mercy of others and, my greatest assets; my IQ is tending towards almost zero”. I think this is a universal apprehension of a person suffering from dementia in later life.

Ms. Priya was recalling her mother, Ms. Aparna Sharma, who had been suffering from Alzheimer’s dementia for the last 5 years and was under my care. We had a long discussion at AIIMS in presence of Dr. A. B. Dey. She came to invite us for the barsy (first death anniversary) of her mother.

“I used to confidently tell my friends about how my mom was getting better. You know Dr. Prasun, I used to think medical science had failed in predicting the case of my mother. You say dementia is a gradually progressing disease [1], wherein after the diagnosis the patient becomes almost vegetative with complete dependence on others for everything [2], all within 5–6 years. But in my mother’s case, she was learning new things and new skills, like writing new sentences with correct spelling, which was a lost skill for her after she was diagnosed with Dementia”.

Ms. Priya was a pampered daughter from an elite family in New Delhi. Her father, Mr. Prabhu Sharma, a business tycoon, always tried to shield her from sufferings; her wish was his command. After completing her post-graduation in journalism, she opted for a job in media in 1990. Life was extremely satisfactory for the family, and she probably thought life would continue to be the same. She continued with a gloomy eyes, “You know, my mother was the home minister of our family; she used to not only care for the family members but was like a mother to all our office bearers. So disciplined even at the age of 79! Above all, she never let my father get depressed when he was wheel chair bound following a massive stroke in 2005”.

She could not hold back her tears and continued after a pause, “It was probably at the end of 2011, when I realized that there were a few things that were not quite right. Ma was little agitated and sometimes lost her patience with workers, which she had never done in past. I could observe better, as I was mostly at home. I had quit my job after my father’s mishap”.

This is a common scenario in India, where a woman in distinct role within a family, such as an eldest daughter, compromises her career to care for and nurture her old and frail parents. Mostly daughters or daughters-in-law are the primary care providers in a majority of the cases (75%), and a vast majority of them are coresidents (98%). Most Indian people live in an extended family set-up. This has become a desirable social situation as there are more people in the household to share responsibility of caring for the frail and old [3]. However, from a caregiving perspective, informal caregiving would put a heavy toll on the family’s economy if the care provider was previously an earning member. Very few Indian families are fortunate to have the luxury of one member leaving the job without affecting the household income, like in Ms. Priya’s case. One study from a village in Tamil Nadu shows that an informal caregiver spends around 38.6 (95% CI 35.3–41.9) hours/week and an estimated annual cost of informal care giving using the proxy good method was US\$119,210 for this rural community [4].

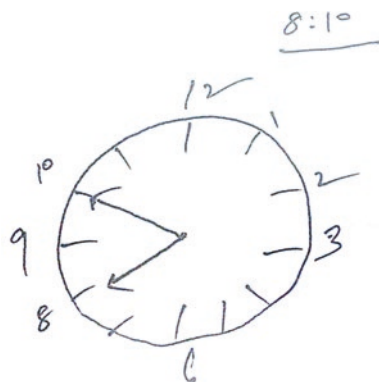
Furthermore, acceptance of the early stage of cognitive impairment is difficult for family members. Denial of such a condition is observed to be the strongest among patients themselves. A confident lady like Ms. Aparna would immediately dismiss such a condition (or to her an accusation) of misplacing things and would instead shift the blame on having to do multiple tasks as part of her daily routine.

In the earliest stage of cognitive impairment (minimal cognitive impairment, MCI), individuals face very subtle inconvenience in any one cognitive domain like naming, thinking and performing executive functions or changes in personalities, misplacing things and difficulty in multitasking. But they are able to manage their daily activities quite well [5]. Eventually, they progress onto moderate to severe dementia in a very short span of time [6]; however, the course is too unpredictable. Ms. Priya did not inform me of her mother’s symptoms at the time of her visit to AIIMS around November 2011. Perhaps, she did not find anything abnormal about these symptoms, or maybe none of the family members were prepared to accept the impending dementia. Ms. Aparna used to visit me for annual check-ups with her daughter. While assessing her cognition, a few notable changes were discovered:

I named three unrelated items: *an apple, a tiger and a pen*. After 3 min, she could recall only two of those items. Then, I asked her to draw a clock and mark 8:10 AM, after which she drew the following picture (Fig. 2.1).

This tool is highly sensitive (~76–99%) [7] to screen cognitive impairment (early memory loss) and can even be performed by a primary physician or a trained healthcare worker [8]. But Ms. Aparna could read 3/3 items as I had asked after 3 min.

Fig. 2.1 A drawing made by the patient



2.2 Multimodal Diagnosis of Cognitive Impairment

I referred Ms. Aparna to our psychologist, Ms. Priti, for neuropsychological assessment and to classify the disease better. The test results suggested MCI and a deficiency in the domains of attention and memory; however, the verbal output was normal. She had minimal cognitive impairment. I informed Ms. Priya and suggested detailed MRI imaging and PET scan to characterize and identify the type of dementia better; however, they were not convinced. Ms. Priya assured me they would do it soon but refused to do it immediately.

After 3 months, in February 2012, the family went in a state of shock when they went to Singapore, and Ms. Aparna lost her way back to the hotel twice. They immediately returned to India and consulted us. We did a quick MRI of the brain and a PET scan, which suggested Alzheimer's disease (AD). The brain MRI revealed hippocampal and temporal atrophy, which is a critical area in the brain for forming memories [9]. Positron emission tomography (PET) suggested involvement of the same areas functionally too. In fact, she deteriorated rapidly from MCI to AD, which is the usual course. Few people are fortunate to have had a slow progression of this disease. Some are luckiest to have MCI halted at an early phase; however, no one can predict the outcome.

Ms. Priya, with the help of a nurse, was a dedicated informal caregiver to her parents. Caregivers play a significant role in managing dementia. Data suggested that 69% of those with moderate dementia and 88% of those with severe dementia depend on support of caregivers. However, the best time for intervention is at the MCI stage. We were too late to start medication for the conundrum called dementia, which is very commonly seen in India. A very few patients get the opportunity to be diagnosed at early phase called MCI; however, sometimes even if they are diagnosed; they are reluctant to start medication.

We started treating Ms. Aparna in July 2012 with our multidisciplinary team, consisting of geriatricians, dieticians, neurologists, psychiatrists, physiotherapists and an occupational therapist from AIIMS. One Ayurvedic doctor from Haridwar joined the team with his suggestions to help her at a later stage. Ms. Aparna used to

visit the Department of Geriatric Medicine of AIIMS on a weekly basis to improve her gait using the gait-balance trainer machine.

In a randomized controlled trial study by Michael Schwenk et al., 61 individuals, with mean age of 81.9 years, who had confirmed mild- to moderate-stage dementia took part in gait and balance training for 3 months at a frequency of 2 times per week for 2 h. They reported that the training helped to show improvement in clinically meaningful gait variables for people with dementia [10].

Ms. Swati Madan, our psychologist, taught cognitive training exercises to Ms. Aparna for a couple of months. Cognitive training exercises work on improving attention, memory and verbal fluency. With such a regime, the patient is given tasks that involve mind games, which are progressively made more difficult later [11].

A young therapist, Ms. Neha, used to visit Ms. Aparna regularly to help her perform daily activities and improve her physical and functional reserve. Her focus was on Ms. Aparna's ability and not on her disabilities: an approach we strongly endorse. Through this exercise regime, she made efforts to improve her muscle strength, endurance and fine motor movement of the upper limbs. She encouraged Ms. Aparna to continue performing her normal chores like gardening, supervising room cleaning and changing her husband's bed, all of which she had been doing previously for the last 50 years or more.

According to Ms. Priya, "Neha would keep Ma engaged the whole day with different types of activities such as eye-hand coordination exercises, balancing, and storytelling. Ma would often sing a few lines of her favorite song- '*Chanda hai tu, mera sooraj hai tu*' (You are my moon, you are my sun). After listening to her, the twinkle in the eyes of my father was amazing; it brought a smile to the face of each member present in the room. I would get nostalgic at this sight; I would be reminded of childhood days when my parents would sing this song together for me and my brother".

Although dementia is primarily a disease of the brain or mental faculty, it involves physical aspects too. Deterioration of motor control occurs as plaques and tangles that affect memory and cognition take hold. This scenario can be a very frustrating and depressing realization for patients to deal with the emotional impact of such life-altering changes [12]. Role of non-pharmacological therapy is very important in managing dementia. Multiple studies have suggested that non-pharmacological therapy is equally or more superior compared to pharmacological therapy. In clinical practice, dementia is mostly handled by a single specialist, while as per evidence, coordinated care among multiple disciplines is very effective. Even patients and their caregiver feel more comfortable to give one, or multiple medicines to their patients with dementia rather than various non-pharmacological therapies like cognitive training, physical therapy and diet plan. Fortunately, Priya and her family members quickly complied with the therapy for her mother (Table 2.1).

The team of psychologist, physiotherapist and occupational therapist and Priya created an individualized daily plan for Ms. Aparna with a sole focus on the following:

Table 2.1 Daily plan for Ms. Aparna created by Ms. Priya, an informal care provider (from March 2012 to March 2013), when Ms. Aparna was in early-to-middle stages of the disease [13, 14]

Morning
Wash, brush teeth, get dressed. Nurse would be present for observation and in case of any help needed
Have breakfast at the lawn while conversing with Priya and Dad
Discuss the newspaper
Reminisce about old memories with pictures and videos of family and friends
Take a break, have some quiet time
Do some chores
Take a walk or play an active game
Afternoon
Have lunch at the dining table
Take a short break or nap
Listen to music, do some simple puzzles, watch TV, or do some gardening
Play 1 h with the therapist Neha
Evening
Chat and discuss over black tea
Play cards or watch a movie
Have dinner at the dining table
Get ready for bed after listening to spiritual music or chanting

- Intellectual activity to prevent slow progression (like playing in computer, video game, Sudoku and basic mathematical calculations)
- Physical activity for personal and family care
- Creative activities (music, art and craft)
- Spiritual and social activities

But everything changed one fine day. Ms. Priya started after a pause, “One fine morning, in the winter of 2013, mom woke up at her usual time of 8 AM, and she came to the garden after performing her routine activities and sat beside me. She started discussing about her achievements and how the different colored roses were adding to the beauty of the day. I listened to her keenly and was observing her vivid thought process towards nature. We were interrupted by a call from our servant who took care of my father and usually was always with him like his shadow. We rushed to his room and discovered that he had not been given his breakfast that day. This used to be a routine procedure carried out by my mother; however, somehow, she missed it that day. She never allowed anybody in the family to take over this responsibility of feeding my father. I felt quite apprehensive when I had to reconcile with the fact that my mother had started forgetting things frequently. So, that day we mutually decided, along with Dr. Prasun, that I should take care of the major activities of the family’s day-to-day practices. I took over the charge of important keys, bank accounts and other significant activities around the house”.

Ms. Aparna's husband, Mr. Prabhu, had a chain of printing presses all over the country. He continued to be the chairman till he suffered from a major stroke at the age of 80. He lost his ability to speak after this episode, and despite the rehabilitation care, he could not move his right hand and leg. Mostly, he was in an electrical wheelchair, which he could regulate only with his left hand. Even for a transfer, he required two caretakers. Akhilesh, Priya's brother, has been the chairman of the printing press business since then; however, Priya was never interested with her family business.

"With time, Ma became more forgetful, more dependent and her gait became slow and unsteady despite regular physiotherapy. Dr. Prasun increased the dose of her medicines. People used to come to our house. Initially, Ma tried to pretend to recognize most of them. But gradually in her downhill course, she could not recognize even the frequent visitors to our home. With each day, she reduced her interactions with outsiders as well as with me".

2.3 Handling Caregiver Stress with Additional Complications

Ms. Priya's challenges increased with each passing day as she had to manage two completely dependent parents. She hired two nurses for 12 h a day. Despite the 360-degree support from health professionals as well as friends, Ms. Priya felt low most of the time. It was very frustrating for her to cope up with her mother's fluctuating condition. There were days when Ms. Aparna would respond well even to the slightest gesture, which would give Ms. Priya hopes of seeing some improvement in her mother. But such days were overshadowed by days when Ms. Aparna was very low with minimal attention and almost no registration. Although fluctuating course is a feature of vascular type of dementia, it may happen in other types too, predominantly the mixed-type one, which is emerging at a rapid pace.

Caregiver stress in the form of anxiety, depression, social withdrawal from friends and activities, insomnia and lack of concentration are caused by a never-ending list of concerns about the future of the older patient [15].

Ms. Priya used to discuss her anxieties, depression and concern for her parents with me; however, in front of her father, she would be active and cheerful because she was the only hope for Mr. Sharma. From a spiritual guru to ayurveda, homoeopathy to unani, she tried everything possible option.

One evening she was discussing her family history of dementia. She told me that her maternal aunt died after suffering from dementia for 5 years. She was also keen to know whether dementia is heritable. I tried to explain her that majority of dementia is not heritable [16]. However, if someone has developed dementia at an earlier age, i.e. before the age 60, there is a greater chance that it would be passed on [16].

Her immediate question was "Why can't we prevent dementia, if it is not curable?"

I understood her concern. I explained to her that what matters the most is “your life style, how you nurture your brain, how religiously you treat the noncommunicable diseases like hypertension, diabetes and how efficiently you manage your stress” [17].

As per recent commission by Lancet 2018, the nine potentially modifiable risk factors are early-life education, i.e. no secondary school education; midlife hypertension, obesity and hearing loss; and late-life smoking, depression, physical inactivity, diabetes and social isolation [18].

Her immediate response was “Why did my mother develop dementia despite healthy life style, no noncommunicable diseases and no other risk factors except she had less education?”

Ms. Priya was curious, “How does education matter?”

I told her “Low educational level increases the vulnerability to cognitive decline due to less cognitive reserve” [19].

She asked “What is cognitive reserve? Can we improve it?”

Cognitive reserve is resilience to [neuropathological](#) damage with ageing. People who have such brain reserve can tolerate more neuropathology without cognitive and functional decline and therefore develop dementia more slowly than those without this type of brain reserve. It could be defined as the ability to optimize or maximize performance through differential recruitment of brain networks and/or alternative [cognitive strategies](#) [20].

Evidence suggested that less cognitive reserve leads to the earlier development of dementia. Furthermore, cumulative exposure to reserve-enhancing factors, like physical exercise, intellectual stimulation or leisure activities, over the lifespan is associated with reduced risk of dementia in late life [21].

The course for any dementia patient varies but is never restricted to only brain-related symptoms. In February 2015, Ms. Aparna developed extreme discomfort while using the bathroom. On investigation, it was revealed to be a urinary tract infection (*Escherichia coli* of $>10^5$) [22]. A recurrence of urinary infection is a common predicament for dementia patients [23] like Ms. Aparna.

When affected by any infection, patients with dementia are often in an acute state of confusion or irrelevant behaviour, as both the conditions lead to a release of the chemical transmitter acetylcholine [23, 24].

We treated Ms. Aparna with adequate and appropriate dosage of oral antibiotics for 10 days. Her condition improved a bit. In fact, at that point, she started doing better than how she was for the past 6 months.

Ms. Aparna started learning alphabets, she was watching family videos with more attention, she started walking with the help of a walker, and she played with our physiotherapist using a ball.

One day, Ms. Priya entered the room to check on her mother. When she was leaving the room, she was startled to hear the voice of her mother after a year. Ms. Aparna called, “Priya, you only come and go. Why don’t you stay with me?” That day was one of the most memorable days for Ms. Priya, and she recalled this incident to all her friends.

Dr. Norman Doidge in his book, *Brain that Changes Itself*, gives a lot of insight on neuroplasticity, i.e. learning new skills at a late age. According to him, “Learning new skills, registering new things even in a senile brain have excellent effect in developing of new circuit which previously we used to think of as impossible” [23]. With the perseverance of Ms. Priya and her team, Ms. Aparna probably learnt new skills by developing a new circuit.

Sadly, she was suffering from recurrent UTIs, which hastened her downhill course. We evaluated for the cause using MRI scan of the pelvis, suspecting inflammation of the kidney because of recurrent bacterial infection (pyelonephritis), but it was not. We also placed her on a prophylactic antibiotic tablet nitrofurantoin (100 mg), which was administered twice daily for 3 months to prevent repeated infections. The strength of dedicated teamwork helped her maintain her partial independence, even though it had been 5 years since she was diagnosed with dementia. The journey was never smooth for Ms. Aparna. In the first week of January 2016, she developed sudden breathlessness and was feverish. I shifted her to AIIMS and kept her in the ICU for treatment of the UTI, lower respiratory tract infection and sepsis, all of which are a common sequel of dementia [25]. Adequate treatment at the correct time with appropriate antibiotics was the key to saving a life. But, in a country with immense possibility of development, very few older adults are lucky enough to have access to healthcare facilities and skilled manpower [26].

Even though Ms. Aparna recovered and went home happily, Ms. Priya was perturbed about future. She was unable to accept that, even with the best of care, her mother may never become perfectly healthy again. Ms. Priya eventually started caring for her actively. She arranged for all essential equipments like oxygen cylinders, pulse, oximeter, injections, etc at home. She would keep checking Ms. Aparna's pulse and blood pressure (BP) even when her mother was normal. As per her friend's suggestion, *Mahamrityunjaya* puja was conducted (dedicated to Lord Shiva) for 7 days with thirty saints from Haridwar for Ms. Aparna's good health.

Ms. Aparna was improving marginally and, with every passing day, her condition made Ms. Priya more confident. Ms. Aparna started walking on her own with the help of a walker, started watching movies and would sing a few lines too. The family was very happy as they were listening to Ms. Aparna after a year of complete silence. Ms. Priya's father was trying to move his paralysed right leg and would ask Ms. Aparna to sing with a sweet gesture.

2.4 Downhill Course and Discussion About Advance Directive

During her mother's ICU admission, we had asked Ms. Priya about an “advance directive” for her mother. Discussion about crucial treatment decisions such as whether we should support anyone by external machine to control the lung (ventilator) is mandatory in a case like Ms. Aparna's who had moderate dementia leading to a dependent life. Ventilator support should not be suggested as it is merely a life-prolonging machine; instead the treatment should add quality life with years of

dignity and autonomy. Patients, who are mentally agile, should decide in advance and give a directive for what should be done in case of emergency. However, for someone like Ms. Aparna, next of kin should take the call after a detailed discussion with family members.

Ms. Priya's response in Dr. Dey office was, "We must do everything to save her. Dr. Dey, you are talking about dignity and autonomy but what about our own emotions? Please don't ask me this question".

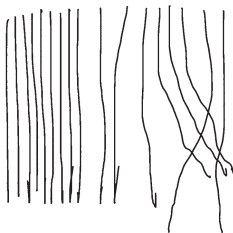
Each passing day was probably a surprise for both Ms. Priya and her father. The family was gradually moving to a mode of acceptance of their fate from a complete denial mode.

In the early summer of 2016, Ms. Priya was busy with certain cultural events at their Bengali colony. Ms. Aparna perceived herself as the head of the family and had always been conscious of her looks. Her hair colour appointment was on Friday, but Ms. Aparna insisted it to be done on the same day through gestures. So, a team of beauticians arrived for her makeover. After almost 4 h, she came to the living room of the house and everyone was left astounded. Her beautiful hair was all black, her face was glowing, and her nails were manicured with red nail paint on them. Ms. Priya loved the expression in her father's eyes who looked at Ms. Aparna with immense adoration.

However, God had something else in store for them. At 4 PM on the same day, when Ms. Priya was busy with the event, she received a call. "*COME HOME...*" she understood. Also, the nurse on duty called me, "Doctor, ma'am is going breathless with saturation falling down to 30%. BP is also low". She cut the call and did not wait for my instruction. Ms. Aparna breathed for the last time at 4:30 PM.

There are so many people like Ms. Aparna in our country who suffer from problems of forgetfulness and related complications; however, they are not fortunate enough to have financial autonomy or a sincere and dedicated caregiver from the next generation. In fact, older adults become dependent only on the spouse who is also old.

2.5 Lonely Couple and Their Fight Against Dementia



Dementia

I can still recall a question asked by Ms. Preeti Gunjan, a physiotherapist, “Sir, can you provide a free sample medicine for dementia?” It was the month of June in the summer of 2013. An elderly couple was waiting in front of my room, and both of them were wearing clothes that looked unwashed for weeks. Mr. Prakash was an 85-year-old, moderately built man, with a walking stick in hand; he had a long moustache like that of the legendary kings of ancient times. He was accompanied by his wife Ms. Sandhya, a 75-year-old lady with spectacles and wrinkles on her forehead who was breathless while at rest. Gunjan brought them to me for some help. AIIMS provides many medicines for free to most OPD patients. But, medicines for dementia are expensive. I saw the prescription and called them to my room. When I asked them some simple questions about their health, Ms. Sandhya started crying. She asked, looking at Mr. Prakash, “What will happen to him, if I die early?” I wondered why she would anticipate this. I asked both of them to sit in the chair and said, “Please relax, Mata Ji. Please tell me what the problem is?” She then narrated her story, which is perhaps the story of millions of other such elderly couples. Who knows, maybe one day, it can be a story of yours or mine!

“My husband used to work as a security guard till the age of 65 years. We saved every possible penny to make a small house of 1000 sq. feet for us at Chattarpur. We tried to give the best to our sons. Our elder son is now doing a clerical job at a government office, and the younger one is working at a shop. The elder son stays at the government quarters and is not ready to accept us as his parents because of our illiteracy. The two-floor house that we built with our hard-earned money is no longer ours with the younger one staying on the first floor, although he does not take care of us. We cook for ourselves, clean our clothes and clean the room as much as possible. There is nobody to help us. The elder son even sends anti-social people to threaten us to vacate the ground floor. The younger son often sends his son (19 years) to beat us and tries to snatch away the property from us”.

After hearing all of this, I asked her if they had already transferred the property in their son's name. She told me that she had not done it yet.

With teary eyes, she continued while lifting her husband's shirt, signalling me to examine him, “Doctor, look at my husband's condition. His back has marks of physical abuse. And can you imagine what his fault was? He had entered their house on the first floor and asked for food. I can control myself without food for two to three days but he cannot. He has lost his insight”.

Memory loss among the older adults can be seen in different forms; it can be forgetting a few things like how Ms. Aparna did in the previous story. It can be in the form of behavioural problems like suspecting others, paranoia and trash talking about others. The behavioural component could be an initial manifestation with a fluctuating course. Mr. Prakash is an example of forgetfulness because of vascular phenomena like multiple, small and unnoticed strokes (often termed as vascular dementia) [27]. Mr. Prakash didn't receive proper medical consultation with doctors, as both his diseases, hypertension and diabetes were silent, without any obvious symptoms.

So, for an illiterate, rather ill-informed caregiver, like Ms. Sandhya, it was initially difficult to understand that changes in his behavioural component were

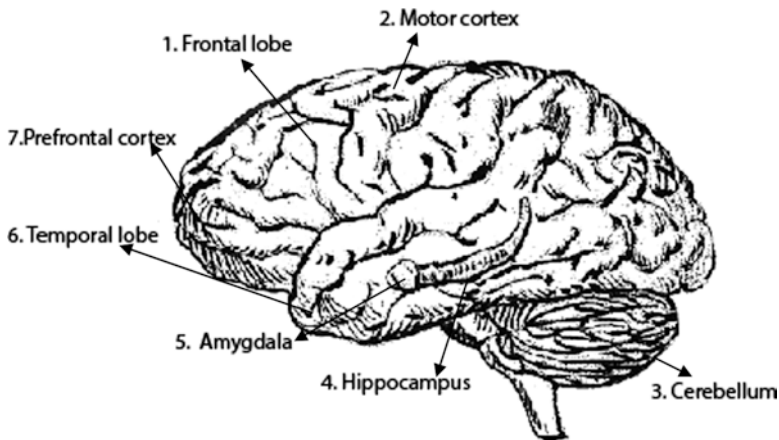


Fig. 2.2 Schematic describing the different parts of the human brain and their role in the human body. (Source: Author)

because of memory loss. We performed an MRI scan for the brain (free of cost), which suggested multiple infarcts (blockage in paths of blood flow to various parts of brain) in certain specific places like the temporoparietal region [28] (Fig. 2.2).

It is widely understood that controlling diseases like hypertension, diabetes and CAD can often prevent vascular dementia. Moreover, both scientific researchers and general public are aware that dementia is partially preventable but not curable [29]. Controlling vascular risk factors like managing diabetes, hypertension by medication and lifestyle modification (such as diet and exercise) have a considerable effect in preventing dementia. Cognitive training, i.e. challenging various components of memory to make it better and create newer circuits and skills, plays an important role [30]. Learning new skill is possible at any age; however, the only problem with older adults is registering new things takes some time [31]. As precautionary measures, methodological guidelines and evidence-based medicines can be used. Woefully, our health system is unable to provide this to the masses.

2.6 Abuse of an Older Adult with Cognitive Impairment

The story I have mentioned is probably just the tip of the iceberg, with similar events happening at every nook and corner of metropolitan cities like Delhi. This is a typical example of elder abuse prevailing as an epidemic in our society because of rapid demographic changes. The results of a study carried out by the NGO HelpAge India [32] showed that one out of five older adults get abused at home. Despite the existence of specific laws to protect them, 98% of the abused victims do not file any complaint. Often, the vulnerable older adults are unaware of the existence of Maintenance and Welfare of Parents and Senior Citizen Act, 2007 [33], which

mandates the next generation or relatives who are either in possession of property or are caretakers of senior citizens, who own it, to be bound to provide food, clothing, residence and medical treatment to their older family members. Most importantly, abuse of any form, verbal, physical, as well as neglect is punishable under law. But the fabric of our society and socio-economic conditions of most Indians has produced a complex narrative for older adults in India. Furthermore, grandchildren are generally close to grandparents because of their friendly nature, non-judgemental attitude and unconditioned love. However, like this story, teenager abusing older adults is also not rare, which is unfortunate and not within the existing social fabrics.

Ms. Sandhya further continued, "Sometimes, my husband is absolutely normal and speaks a lot of sense. We planned to leave for an old age home. But I heard that even old age homes are not a good place to stay. There are moments when he is totally lost. He speaks of irrelevant things. How good those days were when we had a small palace in Rajasthan and a good business of renting our property. But who knows? Maybe we were sinners in our last birth, which would explain all of what is happening to us. We were happy in a joint family. After the death of my father-in-law, my brother-in-law backstabbed us. He got all the property papers signed by my husband in his own favour. This happened because we were illiterate, and my brother-in-law was well educated with an M.A. degree. We left our home with one small suitcase, a breastfeeding child and a 3-year-old son. We shifted to Delhi as we thought that living in Jodhpur was dangerous. My husband could have died of shock. We stayed in a resettlement colony and my husband started working as a security guard in an old colony of Delhi. But once both of our sons came to know of the whole story, they started looking at their father as a loser".

I was speechless and, quite frankly, very shocked and dismayed; I could not imagine how a son and a grandson would beat an old couple. I was heartbroken to hear about their situation, which only made me wonder about the hundreds of other elderly couples who are abused by their children and how most are silent sufferers.

The impression and situation of old age homes of India is even more hopeless. Although it has been created around the model of "assisted living service", which exists in most developed countries where there is adequate support of food, shelter and medical services. Most old age homes in Delhi are run by public or private funds. They are usually completely devoid of medical facilities, and they only provide food and accommodation, which is often quite unhygienic and unsuitable for old age health. Moreover, only physically, psychologically and socially deprived older adults stay in such setups, which is quite a vulnerable environment to spend one's last few days.

2.7 Situation of Poor Older Indian

I was upset and angry for them and at them as well. I allowed Ms. Sandhya to express all her emotions for 20 min and allowed her to sink in. I asked, “Why didn’t you complain to the police? If you want, I can do it on your behalf”. She told, “What good can come of this? They are our own blood”. Perhaps, this is a very common answer.

Mr. Prakash had been listening till now but suddenly he spoke, “We will not go to police”. Although he had moderate dementia, he was able to comprehend some things clearly.

They were surviving with an old age remuneration of only Rs. 1,000 per month, which helped them to have a large meal only thrice a week. For Mr. Prakash, a few neighbours would provide their leftover food so that he could eat the next day.

They did not have a ration card or any other ID proofs. Every identity proof had been snatched away by their sons and daughters-in-law. In a metropolitan city, like Delhi/Mumbai/Kolkata/Bangalore, Rs.1,000 per month or even Rs. 2,000 per month is not enough to have two large meals every day. Financial and social security are equally important like healthcare. Considering more than 66% of older Indians are like Mr. Prakash and from the informal sector, it is a gigantic task for policymakers and the government to ensure that older Indians get food, finance and health security. Even in the era of digital ageing, universal and free health service to the all older adults remains a distant dream. For the past 3 years, we from Department of Geriatric Medicine, AIIMS, have been helping beleaguered couples by providing them with free medicines.

Mr. Prakash’s dementia continued to wax and wane. Ms. Sandhya’s breathing difficulties had increased with progression in her diseases to an advanced stage. Moreover, Mr. Prakash no longer visited us as he was almost bed bound; they could neither afford to come for physiotherapy regularly nor could they afford to pay for a physiotherapist to come home. However, Ms. Sandhya would visit monthly to collect medicines from us for herself and her husband as she was still harbouring a false hope that miracles do happen and that Mr. Prakash would be fine one day. Who knows, maybe he will?

Both these cases demonstrate the wide range of issues that affect and guide the course of dementia, a very common and intense old age condition, in India. While each person and family member experience and perceive [dementia](#) and its progress in their own way, its overall impact is distressing both at an emotional and a physical level. While India is witnessing dementia at an epidemic proportion among the older adults, there is lack of skilled manpower to diagnose dementia at an early stage. Medical education pertaining to dementia and its care is non-existent at both the undergraduate and postgraduate levels. Chen et al. showed that more than 90% of cases related to dementia remain undiagnosed [34].

As the number of older Indians coming from rural India is quite high, basic understanding of dementia, its diagnosis and management must be included in the undergraduate curriculum, and primary care physician must be sensitized to holistically

handle the syndrome. Public awareness and screening at doorstep and at mass level is required not only for the risk factors like HTN/DM/CAD but also for early diagnosis of dementia. Intense coordination with patients, caregivers, doctors and other paramedics can only help to deal with this situation in later life.

Dementia is a clinically complex condition with low awareness and sensitization in the society. Ignorance often leads to indifference of caregivers and care providers because of the subjective complaints of forgetfulness by older adults, which are considered as a normal ageing phenomenon. Even if diagnosis is made, the situation remains grim.

In my patients' language: "Doctor, when I had prostate cancer, family members used to sympathize, but when they realized I had dementia, they began avoiding me and probably cursing me as I would be a fully dependent show piece of the family... the most unfortunate part being that even doctors choose to spend little time with me. He probably considered me useless and chose to invest his time in a more worthwhile undertaking. They still forget that I can appreciate their gesture, affection, ignorance and hatred".

These few lines are from a letter written by Ms. Kalawati Devi who was suffering from early stage of dementia. Often, it depends on the socio-economic conditions of one's family to another to determine the extent to which families can provide these essential services and an environment of caregiving to older adults of the family. While tender care may not be able to decide the fate of an older adult, like in the case of Ms. Priya and Ms. Aparna, it is integral in leading to a meaningful and respectful journey through such a life-altering phase. Caregiver stress is a very prevalent situation. Our society is yet to evolve into a stage of acknowledging and sharing responsibility; the drastically different cases of this chapter are a testimony to that.

Lastly, the sensitivity of medical fraternity needs to be altered when dealing with patients suffering from dementia. Older adults and family members should not ignore the subjective complaints of forgetfulness, which are a harbinger of the development of dementia. Probably, dementia can be prevented with a healthy lifestyle, control or modification of risk factors, and by an early diagnosis [30].

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