



NIKISA Healthcare Pvt. Ltd.



NIKISA DEMENTIA VILLAGE



What is Dementia?

Syndrome:

Dementia represents a group of symptoms that characterize a condition. (But, not Everyone may show all symptoms or the same intensity)

Affect memory, thinking, behaviour etc

Not just the mild forgetfulness seen in old age. The memory loss affects every day life of the patient.

Dementia is a **syndrome**, usually **chronic**, characterized by a **progressive**, global deterioration in intellect including **memory, learning, orientation, language**, comprehension and judgment due to **disease of the brain**. It mainly affects older people: about 2% of cases start before the age of 65 years. After this, the prevalence doubles every five years. Dementia is one of the major causes of disability in late-life.

Chronic & Progressive;

Continues for a long time and progressive as the symptoms keep getting worse

Brain illness

Symptoms happen because of illness that affect the brain. Alzheimer's Disease is one of them, But, there are many others

Dementia pathology

Dementia syndrome is linked to a very large number of underlying causes and diseases in the brain. The common causes accounting for 90% of all cases are Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies and Front temporal dementia. The characteristic symptoms and neuropathological findings are summarized in the table below.

Common subtypes of irreversible dementia

Dementia sub type	Early characteristic dementia	Neuropathology	Proportion of symptom case
Alzheimer's disease (AD)	Impaired memory, apathy and depression, Gradual onset.	Cortical amyloid plaques and neurofibrillary tangles.	50-75%
Vascular dementia (VaD)	Similar to AD, but memory less affected, and mood fluctuations more prominent Physical frailty, Stepwise progression.	<u>Cerebro-vascular disease</u> - Single infarcts in critical regions, or more diffused multi-infarct disease 20-30%	20-30%
Dementia with Lewy bodies (DLB)	Marked fluctuation in cognitive ability, Visual hallucinations, Parkinsonism (tremor and rigidity)	Cortical Lewy bodies (alpha-synuclein)	<5%
<u>FrontoTemporal Dementia (FTD)</u>	Personality changes, Mood changes Disinhibition Language difficulties	No single pathology – damage limited to frontal and temporal lobes	5-10%

Dementia Symptoms & Stages

Different persons show different symptoms of Dementia. The type and intensity of symptoms depend on the underlying illness. Symptoms and their intensity get worse when the illness progresses. While there are different methods of staging dementia, most commonly followed stages are given below;

Early Stage: Symptoms shown are similar to old age. Possible symptoms like forgetfulness, disorientation, difficulty in finding right words, problems in arriving at right decisions, or doing difficult tasks, mood and behaviour changes can be observed.

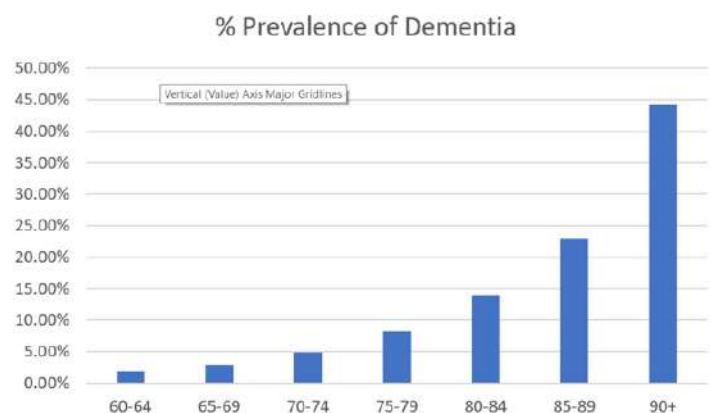
Middle Stage: Symptoms are more obvious. Examples, being more forgetful, needing more help to do normal tasks, More visible behaviour changes, May not recognize persons or objects. Increasing dependence, Communication is difficult.

Later Stages: Person is almost fully dependent for everything. May suffer from incontinence, suffers From mobility problems, Very poor communication, even unable to tell when not well, Eating and swallowing problems increase. Other medical problems increase.

Gets worse as the underlying illness worsens

How many around us have Dementia?

As per a survey whose results were published in 2015, there are 41 lakh elders above the age of 60 years have dementia. This means, 3.7 % of people above 60 years are suffering from dementia. 1 in every 16 households with an elder has some one with Dementia. Any one can get Dementia. Even persons below 60 Years also. Older persons have a higher chance of Dementia. Dementia prevalence doubles for every 6.6 years increase in age. In 90 + age group, 44.1% have Dementia.



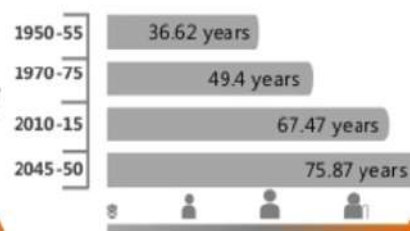
Will Dementia be a major health problem in future?

People are living longer

Older persons (above 60) will be a larger part of the population



Life expectancy if born in...



Impact of Dementia will increase as India ages. Number of aged persons will increase from 8.9 % of population in 2015 to 19.4 % by 2050. Yes. It will possibly a major health issue in future.

The Impact of Dementia on The Individual, family & Society.

India is a diverse country with geographical and socio-cultural differences. We have a rapidly aging population which currently exceeds 100 million. This number will steadily increase in the coming decades. The estimated number of PwD in India is an important indicator of the impact of the disease. However, numbers do not convey the effect on the quality of the individual experience, or the wider consequences on the society. Hence the impact of dementia needs to be understood from three inter-related levels:

- 1. The individual:** The PwD experiences ill health, disability, impaired quality of life and reduced life expectancy.
- 2. The family:** Dementia in one of the family members has an overall impact on the entire family. At this juncture, the family and kinship form the cornerstone of care and support of the PwD in India.
- 3. The society:** The cost of providing care and support to the PwD is met by the society, either directly through government expenditure, or in other ways. The cost of lost productivity needs to be to be accounted for. Other social impacts, like burden may be harder to quantify, but still have to be borne or endured.



Impact of taking care of PwD on the caregivers

Emotional impact on the caregivers

1. The mood of PwD affects the mood of the caregiver who is already tired & facing other problems.
2. Isolation as Caregivers do not get other company.
 1. Others may be critical.
 2. Too much work & cant leave home.
 3. Others may avoid the patient as the PwD can be negative.
3. Difficult to watch PwD declining and dying. Loss of hope can be very sad.
4. Hurts to lose shared memories.
5. Planned retirement plans may not work now, if the caregiver is a spouse.

Resentment & Conflict within the family

1. Unresolved past issues with PwD can lead to conflicts. PwD could have been alcoholic or a wife beater, abuser, or might have harassed the daughter in law. Such issues add on to conflict and ethical dilemmas.
2. Relationship issues can arise as one person(PwD) is taking too much of attention.
3. Major adjustments may affect many other family plans and eat up savings.
4. Disagreements over care decisions and sharing the cost of care.
5. Possible property disputes.

Unsuitability of care giver to provide care

1. Care giver may not be physically capable of giving care on account of poor stamina, repulsive nature of work like handling of diapers, soiled cloths. May have health problems like back ache.
2. Caregiver might have to tolerate physical and oral abuses.
3. May have to learn new techniques of care, which caregiver may find it difficult.
4. As a bread winner of the family may find it tiresome to both attend to work and then taking care pf PwD at home.
5. Economic impact of care might be ruining the family financially.
6. End of life care may be terrible to handle.

Caregiver's fatigue

1. When Care is 24X7X365, and not equally distributed between the family members primary caregiver get more involved and others distance themselves. Caregiving may last years and caregivers burn themselves. Social pressures are difficult to face.
2. Sometimes heart breaking decisions are to be taken alone.
3. Work has no breaks.
4. Readjustment problems can sap a caregiver.
5. Education of children may adversely get affected.

The Concept of Dementia Village

As Dementia progresses the PwD will usually need more assistance from family members, spouse, children, siblings and other relatives or friends. Sometimes a family member leaves his/her job to take care of the PwD. As the dementia worsens, PwD may need someone available around the clock to make sure that he/she doesn't wander off or injure himself/herself. Some patients, but not all, may spend a good part of the night wandering around the house, while sleeping during the day — making it even more stressful for family members). They may need to hire an outside caregiver to help the PwD and provide a break for the family. With continued progression, the PwD may need to be placed in a nursing facility. The nursing staff in a nursing home or hospital can devote a limited amount of time to spend with each PwD. The PwD cannot be allowed to go outside the premises. The PwD, and staff, can become frustrated. Hospitals in India and elsewhere are basically designed to take care of patients in acute phase. They cannot take care of the needs of PwD.



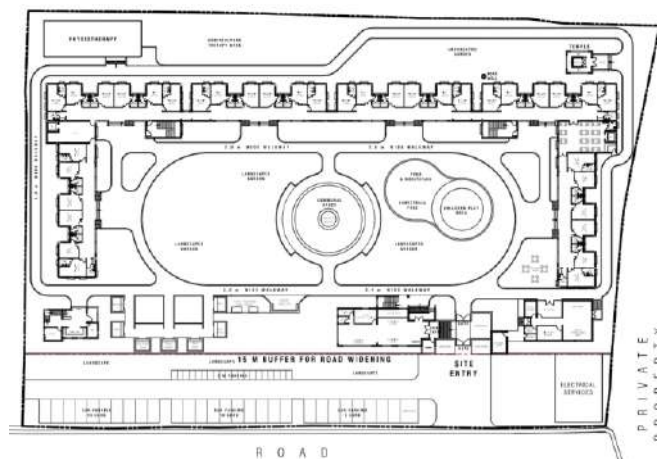
Pictures from Dementia Village, The Netherlands.

In some European countries and in some states of USA and Canada, specialized hospitals called "Dementia Villages" have been established to take care of PwD. In Dementia Villages living environments are customized to provide a very safe and a congenial environment for PwD. PwD are a special category of patients who have to be handled with tender care and caution. The Dementia Village provides safe and congenial environment to PwD so that their physical, clinical and psychological needs are taken care of. The Staff at Dementia Village are specially trained to deal with PwD. 'Dementia village' is actually a dedicated chronic care hospital created to take care of PwD.

NIKISA Dementia Village

NIKISA Dementia Village is set up as a small habitation where PwD can live and receive care. Unlike normal hospitals, in Dementia Village PwD will be allowed to lead a normal life within the confines of Dementia village. Unless the activity is dangerous to the PwD or to others, the PwD will be free to pursue their activities. Curbs will not be placed on PwD. This is "**It is your way**" principle. Some examples given below elucidate this principle.

1. The 2.5acre premises of Dementia Village, is well protected on 4 sides so that the PwD is safe and can walk around the premises as he/she wishes. The patients will be free to leave their rooms and go on walks within the Dementia village anytime or meet with other patients, or visit them in their cottages. While they are allowed to go freely, the manual and camera surveillance system takes care of safety.



2. Instead of residing in 16 bed Nightingale wards the PwD live in well appointed rooms. A set of room constitute a block and the blocks have been created to suit the gender, social background and stage of the disease of the PwD.
3. There is walking street in the Dementia village and it has a departmental store, a coffee shop, a post office and other places for the PwD to visit. These are PwD caring facilities and not real business establishments. The PwDs can go for shopping and can purchase what is available. Even a bill is provided. PwD can take the goods to the ward. After a while, caregivers can distract the PwD, presumably taking advantage of the fact that they have forgotten where they were going, and bring the goods (or the empty pack) back inside the departmental store.

NIKISA DementiaVillage (Contd..)

4. A restaurant will be managed by one of the staff. It functions from 10.30 to 12 am AND 4.00 TO 6.00 pm. This restaurant would not have general menu. Instead a PwD specific menu card would be prepared in consultation with the nutritionist and for reference of the restaurant keeper. Patients are offered menu to eat as per the prescription of the nutritionist and the same is provided as per the prescribed quantity.



5. PwD can get their hair styled at the saloon. They can go any number of times to the saloon. Each time when they go, hair is styled.
4. PwD can see a movie or do anything else that the “village” offers. They can fruits or take any news paper or magazine.



5. These shops and amenities will be operated by real cooks, waiters and other employees who aren't health-care professionals. They're trained to deal with dementia patients. All of the shopkeepers and other employees at the village are trained to deal with PwD.s.
6. The workers at Dementia Village act as cashiers and post office-clerks. But no real transactions take place. No money exchange takes place.

Amenities at NIKISADementia Village

The Wards: PwD stay in “private wards” in each block. The wards are designed to take care of PwD in category C3 to C7. It is expected that patients in category C1 and C2 are not usually admitted in a care center as the impact of dementia would not be debilitating both for the PwD as well as the family members. Some in C3 category may be admitted when the disease is diagnosed and when there is no help available at the home front. C4 is a crucial stage when family members feel the fatigue. PwD in C3 stage is normally physically strong enough to move around, but the cognitive loss is more pronounced and a few PwD might go missing from their homes. Even in home settings, family members often find it difficult. PwD from C3 to C6 stages are often admitted in care homes. In NIKISADementia Village PwD in category C3 to C5 are treated and cared in Special wards and those in advanced stages viz C6 and C7 require higher level of clinical care and therefore cared in the Intensive Care Block or ICU block.





There are six wards in each block. 4 wards are single wards and two are double bed wards. Each ward is provided with cot & bed, sofa units, storage units. They have attached bathrooms with continuous water. The bed is provided with bed spreads, pillows, safety bars, duvets. Rubberized wood flooring in wards contributes to PwD safety. The wards are bright and have sound proof glass windows. Safety bards are installed in windows on the basis of assessment of the PwD. In Double wards a relative of the PwD can also stay. In the Intensive care block PwD who are n C6 and C7 stages are taken care of. This has fowlers bed, nursing station, duty doctors room with facilities for terminal care. As rule Ventilators are not provided in ICU unit.

Amenities at NIKISA Dementia Village (contd)

Reception block: This is at the entrance to Dementia Village. Security personnel guard this block on 24 X 7 basis. The receptionist and Patient Relations Officer also function from this block. The reception block has a Consultation chamber with dressing facility. It has change rooms for staff to change their street dress and wear hospital uniform.

Patent safety: The Entry and Exit gate and the whole premises is under the supervision of security personnel and surveillance cameras on 24 X 7 basis. All wards have both acoustic and movement sensors along with cameras. The Dementia village is free from street dogs, cows, pigs and other stray animals, as well as bee hives, snakes etc. No plant with thorns, white sap, prickles, and allergic bristles is allowed to grow within the premises. Control of external stimuli, especially noise, has been accorded top priority.

Park: Dementia Village has a park area covering 56000 sq ft. All wards face the central park. Landscaped garden watered by sprinkler is a site to watch. The Central avenue has chairs to sit. A fountain at the middle of the Central Avenue is a treat to eyes. Park area is lit with solar power all through the night

Walking track: The Dementia Village provides safe waling tracks. The covered corridor stretches over 450 ft. This apart, inner walking track is about 750 ft. This track is very safe and well lit even during night. PwD can come out of their wards anytime they want and roam around. The outer walking track measuring 950 ft is open from 6.30 to 8.30 Am and 4.30 to 6 PM.



Amenities at NIKISADementia Village (Contd)

Kitchen: The Dementia Village has an independent kitchen block to ensure that fresh diet prescribed by nutritionist is made available to the PwD from time to time. Experienced cooks will prepare the Diet. The PwD will get the Diet that they are normally used to in their life. Apart from normal vegetarian diet which includes rice, chapati and curries, regional food is also provided. If the PwD shows interest the cooks will allow PwD to join them in cooking their food. For the present, only cooked vegetarian food is provided to PwD.



Dining Hall: There is a dining room at Dementia Village. Patients who like the company of others can come here and dine. In addition, in each block dining table is provided so that as a community, the PwD will dine along with fellow PwDs and nursing assistants. Cutlery used are carefully chosen for safe use by the PwD.



Kitchen garden: The Dementia Village grows a large portion of its vegetables it requires right on the campus. This is to ensure that good quality vegetables are available for the residents. A tree garden ensures supply of Curry leaves, drum sticks, lemons, banana and papaya.



Lounge: Dementia Village has a well equipped lounge for celebrating functions by the family members of PwD. In case the family members choose to celebrate birthday of PwD, or want to have any other get-togethers they can utilize lounge and catering facilities of Dementia Village facilities.



Healthcare, Hygiene and Nutrition in Dementia Village:

1. Healthcare:

1. There is a resident doctor to take care of day to day health of PwD.
2. In addition, services of Neurologists and other consultants who are already on the panel of NIKISA healthcare services is obtained as consultants.
3. Physiotherapists provide physiotherapy services to PwD as and when required.
4. There is a minor Operation theater to attend to dressings, injection etc.
5. Two nurses would be on duty in each shift and they would track the vitals of each PwD and attend to issues like injections, Reils tube management, catheter management etc.
6. In addition, a battery of nursing assistants would provide all required services to PwD and live with the PwD.

2. Hygiene:

1. NIKISA has its own water source in the form of a borewell which is yielding potable water. Yet, the drinking water is cleaned through Reverse Osmosis Filters and used for cooking and drinking purposes.
2. Sweeping and mopping of Dementia Village is done by personnel appointed by NIKISA for the purpose.
3. Cleaning of toilets is done by personnel appointed by NIKISA for the purpose.
4. NIKISA staff wear clean uniforms and follow dress and hygiene code prescribed by NIKISA
5. Waste disposal is done as per Medical Waste Management rules.

3. Nutrition:

1. Dementia Village provides vegetarian diet to all the resident PwD. Day wise menu is framed and provided. Special needs of patients suffering from diabetes, hypertension, hyponatria, kidney failure, etc will also be considered.
2. External food of any kind will not be allowed to be brought by anybody into the Dementia village.
3. Attached to the Dementia Village is a restaurant where PwD visitors' and others can purchase food.
4. Visitors and family members will be allowed to celebrate important days along with the PwD, subject to certain simple conditions enforced by NIKISA Dementia village.

Therapies available at Dementia Village

Minor OT: The Dementia Village has a minor Operation theater which can be used for injections, wound dressing and minor procedures. For small procedures the PwD are not referred to hospitals.



Physiotherapy: The Dementia Village has a very well equipped Physiotherapy unit and PwD will get services of the Physiotherapists as and when required.



Memory Clinic: A memory clinic is set up at Dementia Village for proper assessment and staging of PwD. Residing PwD will be assessed through periodical memory clinics to tracking the prognosis.



Music Therapy: Exactly in the center of the Dementia village has been created. On either side of this road well laid park is located. There is a fountain at the center around which are placed benches so that PwD can enjoy the serenity of Dementia village with Music.



Horticulture Therapy: There are reports that involving PwD in horticultural activity can help them to get meaningfully engaged and such actions contribute to improved quality of living.



Spiritual Therapy: There is a temple (Prayer hall) within the Dementia village. Patients who wish can visit this temple and get spiritual solace.



Nursing Assistants at Dementia Village

Nursing Assistants are persons who assist nurses in the provision of nursing care. They assist the PwD in daily living activities, such as bathing, dressing, positioning, transferring, ambulating, feeding, and toileting. Nursing assistants do not perform any clinical function like measuring vital signs, drug administration etc. They live with PwD in the block. Nursing Assistants of similar gender are provided to each PwD on one to one basis.

In the absence of specialised cadre of Nursing assistants, NIKISA recruits matriculates and trains them to perform their role effectively. Apart from ensuring personal hygiene they are trained some basic skills. Some of the skills imparted to them are given below;

1. Pressure Ulcer Prevention Skills
2. Securing the positioned Foley catheter / bags/ tubing
3. Keeping watch on Oxygen administration including pulse oximeter
4. Recognising irritation and discomfort being felt by PwD.
5. Changing of bed sheets and draw sheets from occupied beds.
6. Applying Cold Compress
7. Measuring and recording of fluid intake.
8. A few other skills.



The issue of Nursing assistants wearing an uniform was examined in detail and it was felt that it is better to post Nursing Assistants with comfortable uniforms to take care of PwD. Nursing assistant lives with the PwD on 24 X 7 basis. Nursing assistants do not perform any clinical functions. They are performed by Nurses.

A normal day at Dementia Village

The day starts by 6.30 am. The nursing attendants will take the patient for a morning walk/stroll in the fresh gardens. There will be a yoga sessions for which interested patients can attend or watch those who exercise. The nursing staff at Nikisa Dementia Village and Alzheimer's hospital will visit patients in the morning to record vitals. Doctor will immediately check the patients who have suffering from some acute problems, like fever or cold or minor injury etc.

Patients return to their room for a bath and grooming. They are accompanied to the common dining area where they are served breakfast. They will be assisted by a team of cooks and caretakers. Following breakfast, patients can indulge in activities such as horticulture therapy, physiotherapy, memory clinics and other group activities. The nursing staff at Nikisa Dementia Village and Alzheimer's hospital will dispense the prescribed medication to the patient post breakfast. Doctor will be available in the doctor's cabin if the patient has the urge to see a doctor.

By 1.00 Pm, patients are again accompanied to the dining lounge for Lunch. They retire for a quick nap post lunch. Medicine if any will be administered by the nurse.

By 4.00 Pm, patients are again taken out on a walk by the staff of Nikisa Dementia Village. They can spend time in the gardens, watching the staff play a game of badminton. They can also spend time in the meditation at the temple. There will be a small snack bar which serves tea, coffee and finger food for the patients who feel like having a quick bite. During these activities, some staff members will act the role of fruit vendors, newspaper seller and grocery store manager.

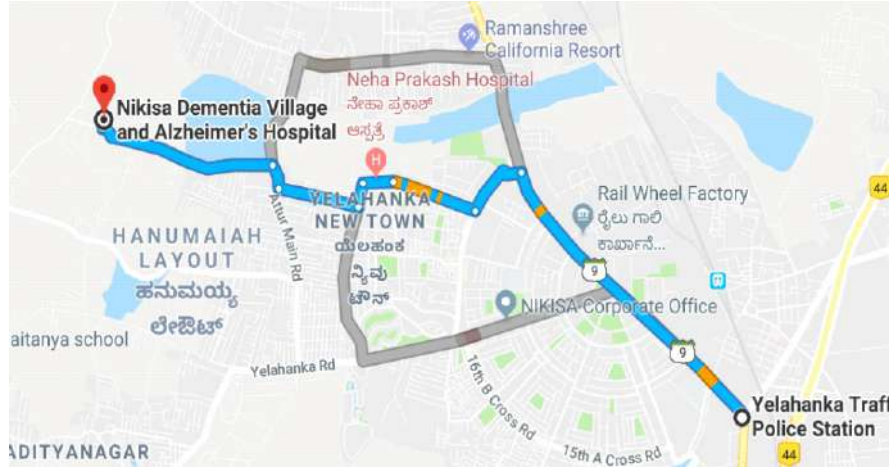
Patients retire to their rooms by 7.00 Pm for a wash and head to the dining lounge for dinner by 7.30 Pm. Post dinner, patients can gather to watch television or sit in a group to have a chat. The nurse of Nikisa Dementia Village and Alzheimer's Hospital will again visit the patient in the night to ensure proper medication for the hour is given. By 9.00 Pm, the patient is asleep in their beds.

On some days music concert or spiritual discourses are also organised. All festivals and birthdays of PwD are celebrated, thus there is one or the other activity every day.



NIKISA Healthcare Services Pvt. Ltd.

How to reach Dementia Village & Alzheimer's Hospital



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