"It is not sufficient to add years to life, but the more important objective is to add life to years" – World Health Organization (WHO) Slogan.

India with an elderly population of nearly 76 million, constituting 7.7% of the total is amongst the top ten nations in this category. At present one out of every seven elderly persons in the world is an Indian. By the year 2020 it is estimated that the population of the elderly will be increased to 142 million or about 11% of the country’s population. Our life expectancy was only 40 years at the time of independence in 1947 with a very high birth rate. This resulted in a pyramidal demographic pattern, in which children constituted the broad base, while the apex of the pyramid was made up of a small number of aged people. As health parameters have improved, this pyramid has become smaller at the base, acquired a broader middle and a higher apex. It reflects the present birth rate which is lower, a broader, economically active young and middle aged population, and a larger number of ageing people, which is growing even large as we advance Life expectancy in India for males is 57.7 years and for Females is 58.1 years; in USA for males it is 73 and for females it is 79.

Life expectancy in Kerala is over 70 years which compares well with advanced societies like that of USA where it is about 76 years. Kerala has a population about 31.84 million, out of which the population over the age of 65 is about 10% (in the USA the corresponding figure is 13%). This segment is the fastest growing at 3.5% per annum where as the population growth rate in Kerala is about 1% per annum. So the elderly are fast growing in numbers. (Sunil K., 200 ).
1.1 PROCESS OF AGEING

As a person grows older, there is a process of natural dying of various cells and a slow erosion of one’s faculties, physical & mental. In fact, from the moment of our birth, there is a biological death clock that starts ticking. This determines the rate of natural growth and dying out and is programmed into the genetic code of each cell. How this dying out process is calibrated and set is still a great mystery, except that genetic factors are primarily responsible. Environmental and toxic factors also have a role in this process. The brain cells are no exception to this and with age, they too gradually undergo a process of natural ageing & death. However, the rate at which this process occurs is never severe enough to affect the person’s daily mental and thinking faculties so that he is never incapacitated in his routine day to day activities.

Occasionally, however, this process of brain cell attrition and death may occur faster than usual, resulting in the impairment of one’s faculties, severe enough to be detrimental to one’s daily activities. This is the abnormal brain-cell death, which may be the result of identifiable diseases or toxic factors (multiple strokes, alcohol abuse, syphilis or AIDS), inherited diseases (like Huntington’s chorea) or diseases of as yet unknown causes (like Alzheimer’s disease).

As one grows older, the chance of developing dementia becomes higher. This is understandable as the dementing process seems to be a result of accelerated ageing (due to multiple causes). Between the ages of 60 and 65, (the young old), the chances of developing dementia are about 5%. This increases by 5% for every 5 years of advancing age, so that by 80 years of age, a person has a 20% chance of being demented. It is estimated that by the 2011 census, 10% of India’s population will be above 60. This gives us an idea of the magnitude of the imminent problem.
In Kerala, this is going to be a serious public health problem since the elderly constitute 10% of the state population. It is estimated that by 2011, 13% of the population in Kerala will be above 60. Moreover, this state has more women than men and the women live longer than men. This is going to produce the unique problem of having a large number of elderly widows in this state. Social changes will also be adding to the problem. The breakup of the joint family system has been fairly rapid and so the support of the elderly has become increasingly the responsibility of the children. Large numbers of our work force are employed outside the state or in the Gulf, leaving many elderly parents back home to fend for themselves.

1.2 WHAT IS DEMENTIA?

Dementia is a syndrome due to the disease of the brain, usually of chronic or progressive nature in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement, impairment of cognitive functions accompanied and occasionally preceded by deterioration in emotional control, social behaviour or motivation. (International classification of disease ICD 10).

Dementia is the gradually progressive, acquired loss of cognitive faculties of the brain, in multiple domains of functions, in an alert, fully conscious patient. Each of these terms requires a little elucidation. Cognition is the ability to act reasonably and logically in a given set of circumstances and it is the loss of this logical, deductive process that occurs in dementia. Moreover, normal brain functioning involves various domains-memory, logical thinking and planning abstract thinking, visuospatial integration and the processing of various incoming stimuli in the visual, tactile and auditory areas. Dementia results in the loss of more than one of these realms.
Mr. Harry Caytol, Executive Director of Alzheimer’s disease Society, UK says that there has been a huge change in the incidence of dementia in the world. It is no longer thought that dementia is an inevitable consequence of age. It is a disease process that must be susceptible to treatment.

1.3 EPIDEMIOLOGY OF DEMENTIA

The number of people with dementia is rising quickly in the world. It is estimated that by 2025, there will be four times the number of people with dementia in the developing world as there were in 1980. Besides 71% of all people with dementia will be in developing countries 2025 i.e., 24 million people.

At present there are 18 million people affected with dementia across the world and 66% of them is living in developing countries. India currently has the burden of 4 million dementia persons. The prevalence estimates in India suggest that 3 to 7% over 60 years have dementia and about half of them are Alzheimer’s type (Rajkumar S, 1997). Shaji et al (2002) gives the prevalence rate of dementia as 34 per 1000 in the urban study.

The following table shows the prevalence rate of dementia.

<table>
<thead>
<tr>
<th>Age</th>
<th>Prevalence/1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>60 - 79</td>
<td>3.59</td>
</tr>
<tr>
<td>70 - 79</td>
<td>20.59</td>
</tr>
<tr>
<td>80 - 89</td>
<td>155.5</td>
</tr>
<tr>
<td>90 +</td>
<td>272.5</td>
</tr>
</tbody>
</table>

(Shaji et al, 1994)

There are very few community-based studies of dementia in India. Rajkumar et al (1996) conducted a study in the city of Madras using a sample comprised of 1,300 people, aged 65 years and above and obtained a prevalence rate of 2.7 per cent for dementia.
Rajkumar et al (1996) who conducted a study in a rural population of Tamil Nadu using a sample of 750 people aged 60 years and above, obtained a prevalence rate of 6.5 per cent. Shaji et al (1996) conducted an epidemiological study in a rural community in Kerala and reported a prevalence rate of 3.4 per cent. In 1998, Chandra et al conducted a study in a rural elderly Hindi speaking population of Ballabgarh in Northern India and found an overall prevalence rate of 0.84 per cent for all dementias in the population aged 55 years and above and an overall prevalence rate of 1.36 per cent in the population aged 65 years and older. A major study titled “Prevalence of dementia in an Urban Community” conducted by Alzheimer’s and Related Disorders Society of India is progressing at Cochin.

1.4 THE SYMPTOMS OF DEMENTIA

Every person is unique and dementia affects people differently - no two people will follow exactly the same course. An individual’s personality, general health and social situation are all important factors in determining the impact of dementia on him or her.

The common symptoms of dementia are:

1.4.1 Memory loss:

Declining memory, especially short-term memory is the most common early symptom of dementia. People with ordinary forgetfulness can still remember other facts associated with the thing they have forgotten. For example they may briefly forget their next door neighbour’s name but they still know the person they are talking to is their next door neighbour. A person with dementia will not only forget their neighbour’s name but also the context.
1.4.2 Difficulty in performing familiar tasks:

People with dementia often find it hard to complete familiar everyday tasks that usually do not require any thought. A person with dementia may not know in what order to put clothes on or the steps for preparing a meal.

1.4.3 Problems with language:

Occasionally everyone has trouble in finding the right word but a person with dementia often forgets simple words or substitute unusual words making speech or writing hard to understand.

1.4.4 Disorientation to time and place:

We sometimes forget the day of the week for where we are going, but people with dementia can become lost in familiar places such as the road they live in forget where they are or how they got there, and not know how to get back home. A person with dementia may also confuse night and day.

1.4.5 Poor or decreased judgment:

People with dementia may dress inappropriately, wearing several layers of clothes on a warm day or very little on a cold day.

1.4.6 Problems with keeping track of things:

A person with dementia may find it difficult to follow a conversation or keep up with paying their bills.
1.4.7 Misplacing things:

Anyone can temporarily misplace his or her wallet or keys. A person with dementia may put things in unusual places such as an iron in the fridge or a wristwatch in the sugar bowl.

1.4.8 Changes in mood or behaviour:

Everyone can become sad or moody from time to time. A person with dementia may become unusually emotional and experience rapid mood swings for no apparent reason. A person with dementia may also show less emotion than was usual previously.

1.4.9 Changes in personality:

A person with dementia may seem different from his or her usual self in ways that are difficult to pinpoint. They may become suspicious, irritable, depressed, apathetic or anxious and agitated especially in situations where memory problems are causing difficulties.

1.4.10 Loss of initiative:

At times, everyone can become tired of housework, business activities or social obligations. However, a person with dementia may become very passive, sitting in front of the television for hours, sleeping more than usual, or appearing to lose interest in hobbies.

1.5 FOUR STEPS TO RECOGNIZING DEMENTIA

1.5.1 Recognize the early symptoms:

Poor memory or any of the other symptoms of dementia should be acknowledged and investigated. We should not assume that they are just a ‘normal’ part of ageing.
1.5.2 Listen to the person:

Most people experiencing memory problems or other symptoms that occur in dementia will not have dementia. Depression may cause similar symptoms and this also needs to be identified and treated. Even if no cause can be identified, a person may be worried and will want to discuss the symptoms; reassurance and explanation are important aspects of care. Sometimes it is helpful to arrange a further assessment after size to twelve months to review the situation.

1.5.3 Listen to the carer:

One of the best ways to identify dementia is to listen carefully to someone who knows the person well. This may be the person’s spouse, a family carer or a close friend. A story of developing memory loss and mental decline is particularly important and requires further investigation.

1.5.4 Seek professional advice:

If you are concerned that you or a member of your family has some of the symptoms of dementia, then seek professional advice. This will depend on what health facilities there are in your community. Sometimes referral to a specialist may be needed where the diagnosis is difficult.

1.6 COMMON CAUSES OF THE DEMENTIA

- Alzheimer's disease (AD)
- Vascular dementia
- Fronto temporal dementia
- Dementia associated with Lewy bodies (DLB)
- Alzheimer’s disease and vascular dementia (mixed dementia)
• Depression
• Metabolic disorders
• Drug intoxication
• Infections
• Structural lesions
• Dementia secondary to alcohol
• Hydrocephalus

1.6.1 Alzheimer's disease

Alois Alzheimer, a German Neurologist first described this illness in 1907. Alzheimer's disease is a degenerative brain disease, which affects memory, thinking, behaviour and emotion. It is the most common form of dementia.

Alzheimer's disease probably represents 55 percent of all Dementia, after the age of 75. Alzheimer's is the fourth leading cause of death. The key element that differentiates Alzheimer's disease from other types of Dementias is, its insidious onset and progressive deteriorating course. It usually leads to death in about 7 to 10 years, but it can progress more quickly (three to four years) or more slowly (as much as 15 years). The prevalence rate shows that approximately 5% over the age of 65 and 20% of those over 85 years are affected with Alzheimer's disease at any time.

In India it has been called "Sathaya gaya" which translates to "turned 60". Another name for it is "Satar - batar" which translated to "turned 70". In researching the origin of these words they appear to apply to altered behaviour and loss of memory in the older age groups. Both these terms probably indicate Alzheimer's disease. Ayurvedic physicians call this "Smriti Bhransh" and described it as early as 800 B.C. "Smriti" in Sanskrit means memory and "Bhransh" is loss.
Millions and millions dollars have been spent in trying to find out the risk factors for Alzheimer’s disease. However, only two established risk factors have been discovered. First is increasing age and another is genetic predisposition. Besides, many other risk factors have been implicated such as viral infection, aluminium poisoning, elderly mothers at birth of the dementia patient, family history of other genetic defects etc. However none of these factors have been found to increase the risk of Alzheimer’s disease (AD).

a) What happens in Alzheimer’s disease?

Essentially there is a premature ageing and accelerated cell death, which is restricted to the brain cells, while the body remains healthy. This results in a shrinking or atrophy of the brain with intercellular connections being snapped. It effectively short circuits the electrical activity of the brain at various places, resulting in distorted and aberrant neuronal transmission, which in turn produces misinterpretations of incoming sensory signals and outgoing verbal and motor commands. This is what leads to a decline in the patient’s mental faculties.

Pathologically the brain gets seeded with senile plaques small discs of an amyloid protein that are surrounded by the remnants of nerve cells called neurofibrillary tangles. This happens in even the normally aging brain, but in Alzheimer’s the process is far more intense and widespread, resulting in the disruption of neuronal circuits.

There are also alterations in the specific messenger chemicals of the brain (Neurotransmitters). A significant decline has been detected in the chemical messenger Acetylcholine, because of the specific deficiency in a catalytic enzyme, Choline Acetyl Transferase. Other neurotransmitters like Adrenaline and Serotonin are also deranged, but no specific causative link could be attributed to them so far. The identification of the deficiency of Acetylcholine has offered a possible clue to a method of treatment of Alzheimer’s. Drugs like Tacrine and Rivastigmine reduce the breakdown of Acetylcholine,
thus helping to sustain its level for longer periods. This has offered some promise in slowing down the relentless progression of the disease.

b) What triggers off these abnormal changes remains a mystery

A small proportion of patients with Alzheimer’s have a similar condition affecting close relatives the inherited variety of the disease. The aberration here has been identified to be located on some chromosomes (1 and 14) or due to aberrant lipoproteins. This genetic pre disposition however does not explain the cause in the vast majority of patients with Alzheimer’s. Since the specific causative factors remain in the realm of conjuncture, a large number of possible culprits have been implicated such as viruses, toxins and increased aluminium in the cells. None of these have conclusively been held responsible for causing Alzheimer’s disease.

c) What is new in Alzheimer’s disease?

A lot of new discoveries have been made in the field of Alzheimer’s disease in the last decade. These involve the areas of genetics, pathophysiology and therapeutics.

As mentioned before, Alzheimer’s disease is usually a sporadic disease. However in a small percentage of patients there is a familial incidence. It has long been known that some of the pathological changes in the brain resemble the changes seen in Down’s syndrome and this was a clue to the possibility that the abnormality lay in the chromosome 21, where the Down’s defect was. The defect in the gene here results in the formation of abnormal amounts of Beta amyloid protein (BAP), which is also slightly different in composition from the normal Beta amyloid protein (BAP). This gets deposited in the brain to form senile plaques.

Subsequently abnormal genes have been found in other chromosomes. An abnormality in chromosome 14 results in the formation of Presenellin 1, while another abnormality in chromosome 1 results in Presenellin 2. Both these forms result in inherited
Alzheimer's disease with different characteristic age of onset and rates of progression. On the other view, an abnormality in Chromosome 19 results in the formation of the E4 allele of the Apolipoprotein. This produces an increased risk of Alzheimer's disease, though it does not invariably lead to Alzheimer's disease in all cases.

The recent unravelling of the genetic code has now allowed us a method of possibly understanding the exact sequence of the abnormal genes, and the way these gene products (proteins) go on to produce Alzheimer's disease. This method allows us to modify and correct the genetic abnormality in the future or block the deleterious effects of the gene products by genetic engineering. This is an area of great promise.

1.6.2 Vascular dementia

The diagnosis of vascular dementia requires three characteristics: presence of dementia, evidence of cerebral vascular disease (history, clinical examination, brain imaging), and a reasonable temporal relationship between the two disorders. A number of clinical features help distinguish vascular dementia from Alzheimer's disease (AD): (1) stepwise deterioration (as opposed to steady progression in AD); (2) history of unsteadiness or unprovoked falls; (3) pseudobulbar palsy; (4) urinary frequency or urgency not explained by urologic disease; and (5) personality and mood changes, abulia (extreme lack of initiative), depression or other sub cortical deficits, including psychomotor retardation and deficits in executive function. Risk factors for stroke (such as hypertension) are also suggestive.

Focal neurological symptoms are frequently present on examination including asymmetric weakness, asymmetric deep tendon reflexes, an extensor plantar response, visual field deficits, and gait abnormalities. Changes in mood and psychiatric presentations along with gait disturbances and early incontinence are suggestive of vascular dementia.
CRITERIA FOR VASCULAR DEMENTIA

a) Probable vascular dementia

  Dementia is defined by cognitive decline from a previously higher level in 3 areas of functions including memory; evidence of cerebrovascular disease by neurologic exam and neuro imaging; and the onset of dementia is either abrupt or within 3 months of a recognized stroke.

b) Possible vascular dementia

  Dementia in the absence of either neuro imaging evidence of infarction or in the absence of a clear temporal relationship between dementia and stroke.

c) Definite vascular dementia

  Clinical probable vascular dementia plus histopathologic evidence of infarction in the absence of other histological markers of dementia (e.g. plaques, tangles, Pick bodies, etc).

  The co-existence of Alzheimer’s disease and vascular dementia, the so-called mixed dementia, may be seen in 10% of demented patients and complicates the clinical pathologic picture.

1.6.3 Dementia associated with lewy bodies

  If extra pyramidal features are present in patients with a cognitive impairment of insidious onset, dementia associated with Lewy bodies or Parkinsonism becomes a possibility. The extra pyramidal signs usually involve bradykinesia and rigidity and typically lack a resting tremor. These patients may also have psychiatric features such as visual hallucinations and fluctuating level of consciousness, although this latter symptom can be difficult to document. The cognitive profile of these subjects may be somewhat different from typical Alzheimer’s disease and may have greater subcortical, attentional,
cognitive flexibility and visuospatial impairments including reduced verbal fluency. Several reports have suggested that these patients may progress more rapidly; unfortunately, the clinical and neuropsychological profiles of these patients have not been sufficiently well characterized to allow the clinician to predict the clinical course.

1.6.4 Frontotemporal dementias

From a clinical standpoint, when the dementia presents with alterations in emotion, affect and behaviour, a fronto temporal dementia should be considered. The typical features include the early appearance of personality changes, withdrawal, lack of insight and disinhibition. These changes are seen in the setting of relatively preserved memory and visuospatial functions.

1.6.5 Other dementias

When a dementia is accompanied by other neurologic features such as extrapyramidal signs, eye movement abnormalities, or progressive apraxia, several other disorders need to be considered. In addition to the dementia associated with Lewy bodies, Parkinson's disease itself can be accompanied by a dementia. A cognitive decline is seen commonly in patients with Parkinson's disease and may involve most patients by the time of death. In progressive supranuclear palsy, patients may have a cognitive impairment along with characteristic loss of volitional vertical eye movements, axial rigidity, and frequent falls. If progressive apraxia is a prominent feature along with asymmetric rigidity and a subcortical pattern of cognitive impairment, corticobasal degeneration becomes a possibility. These disorders may have a prominent dementia, but their other neurologic symptoms make them more apparent.

If the dementia is rapidly progressive and is accompanied by motor symptoms, Creutzfeldt-Jakob disease needs to be considered. These patients may have generalized
myoclonus, ataxia, and a psychiatric presentation, and the characteristic pathology is a spongiform encephalopathy.

In a rapidly progressive dementia, other considerations such as limbic encephalitis or a paraneoplastic syndrome need to be considered. If a gait disorder is an early feature accompanied by incontinence, normal pressure hydrocephalus can be entertained. The size of the ventricles relative to the degree of cortical atrophy can also be important features.

1.6.6 Depression

Depression can produce cognitive dysfunction, including memory problems, slowed response speed and impairment of reasoning and executive function. This combination of cognitive and emotional symptoms has been referred to as depressive pseudo dementia, or dementia syndrome of depression. About 10 percent of patients admitted to psychiatric or neurologic services have depressive pseudo dementia.

Despite some similarities between cognitive deficits produced by depression and those produced by Alzheimer's disease, a number of characteristics differ. The onset of depression is typically acute, whereas Alzheimer's disease has an insidious onset. Depressed patients often readily discuss their cognitive problems, often exaggerating them, whereas Alzheimer's dementia patients tend to deny or minimize these problems. Memory deficits in depressed patients tend to be related to attention and concentration, leading to poor organization and storage. Memory deficits in Alzheimer's disease are related to rapid forgetting of information. When confronted with cognitive tasks, depressed patients often exhibit little effort, typically responding with "I don't know". Alzheimer's dementia patients, in contrast tend to work effectively. On cognitive tasks depressed patients make errors of omission, whereas patients not errors of commission. Depressed patients rarely exhibit dyspraxia, anomia, or agnosia, which are all common in Alzheimer's disease. Finally, cognitive symptoms improve as the depression resolves.
Many early Alzheimer's dementia patients are aware of their deficits and this awareness can lead to depressive symptoms. Because depression can coexist with Alzheimer's disease, it can be approximate to diagnose and treat both conditions.

1.7 NATURE OF DEMENTIA

The onset of dementia is normally very slow and the changes described can come about over a number of years.

1.7.1 Mild Dementia

Often this phase is only apparent when looking back; at the time it may be missed or put down to 'old age', 'overwork', 'laziness' etc. The start of dementia is very gradual and it is often impossible to identify the exact time it started.

The person may be:

- Apathetic
- Less interested in hobbies and activities
- Unwilling to try new things
- Unable to adapt to change
- Less good at making decisions or plans
- Slower to grasp complex ideas
- Ready to blame others for 'stealing' mislaid items
- More self centered, less concerned with others and their feelings
- More forgetful of details of recent events
- More likely to repeat themselves or lose the thread of conversations
- More irritable or upset if they fail at something.
1.7.2 Moderate Dementia

- Here the problems are more apparent and disabling. The person may:

- Be forgetful of recent events – memory for distant past generally seems better, but some details may be forgotten or confused.

- Be confused regarding time and place, and time of day—may go out shopping at night.

- Rapidly become lost if out of familiar surroundings.

- Forgets names of friends or family or confuse only family member with another.

- Forget saucepans, kettles left on a stove, may leave gas burners unlit.

- Wander around streets, perhaps at night; sometimes becoming completely lost.

- Behave inappropriately e.g. going outdoors in nightwear.

- See or hear things that are not there.

- Become very repetitive.

- Be neglectful of hygiene or eating (perhaps saying they have had a bath or a meal they have not).

- Become angry or upset or distressed very rapidly.

1.7.3 Severe Dementia

Here the person is severely disabled and needs a great need of help. The person may:

- Be unable to find their way around.
• Be unable to remember for even a few minutes that they have, for example, just had a meal.

• Constantly repeat one or more phrases or sounds.

• Be incontinent of urine and/or faeces.

• Show no recognition of friends and relatives.

• Need help or supervision with feeding, washing, bathing, using the toilet and dressing.

• Take their clothes off inappropriately.

• Fails to recognize everyday objects.

• Have difficulty in understanding what is said to them, and their speak may make little sense.

• Be disturbed at night.

• Be restless, perhaps looking for a long-dead relative or for a small child now grown-up.

• Be aggressive, especially when feeling threatened or closed in.

• Have difficulty in walking, eventually perhaps becoming confined to a wheel-chair.

1.8 PROBLEMS OF DEMENTIA IN INDIA

It is estimated that there are four million dementia patients in India and the number of them will be increasing in due course. The available data shows that by 2020 India will be the most affected country in the world with vast number of dementia patients. Some of the important features and problems of dementia in India are the following:
• Dementia is the most difficult disease of old age to assist and manage

• Dementia suffers permanently lose their capacity to live independently and over the years even personal care skills will be lost. At that point they require continuous and constant attention from the caregivers.

• In the early stage, Dementias are often misunderstood by the families because they seem grumpy and antagonistic. This exacerbates the distress of dementia and causes severe interpersonal strain in the family.

• The demented elderly are often ridiculed in their community.

• In urban setting the husband and wife may be both employed hence they do not have any other options than locking the demented persons inside the home.

• There is no information about dementia relevant to Indians in their local languages.

• There are no trained personnel with specialized skills for providing good care.

• The joint families have given way to nuclear families. Joint families, in villages are also breaking up with the younger generation shifting to cities and the elderly left behind. Similarly in cities, many times the young once go abroad, while the aged are left behind.

• India has very limited number of institutions to look after the aged and demented. Day care centres and old age homes are nearly non-existent, if compared to the number of aged. Similarly geriatric clinics not at all exist in most of the hospitals.

• Women, the traditional care givers for the elderly demented are increasingly taking to jobs.

• The highly educated women folk have been encouraged to develop aspirations beyond the daily duties of family and there is understandable reluctance to prioritise the often unthanked daily care of a demented in-law.
1.9 DIAGNOSIS OF DEMETIA

Diagnosis of dementia is mainly based on history and clinical examination. The earliest symptoms of Dementia may pass unrecognised because they are so mild that observers consider them to be just normal signs of ageing. Screening instruments like short portable mental status questionnaire - (SPMSQ) and mini mental status examination MMSE are found useful in clinical practices as well as for screening the community. SPMSQ is a slightly modified version that can be used in India and can be easily incorporated in clinical setting.

1.9.1 History

The history is an essential component of the diagnosis of dementia. Multiple rating scales are available for assessing activities of daily living, but ultimately taking a careful history from the patient and family is the best for this assessment. Important aspects of the history include an assessment of change from a prior level of performance including household activities, cooking, cleaning, handling finances, driving, social activities, hobbies, personality changes involving social interactions, changes in affect and social responsiveness. Assessment of changes in cognitive function should also be investigated, e.g., forgetfulness, diminished attention, language difficulties, visuospatial problems, e.g., getting lost and impaired judgement. In addition, inquiries should be made about sleep-wake cycles, gait, incontinence, movement disorders, e.g., myoclonic jerks, and other aspects of the neurological review of system. Finally, the temporal course of the change in cognitive function is important. A gradual onset with insidious progression suggests a degenerative process whereas a more abrupt onset and episodic changes along the course may suggest a vascular component. A more rapid course over a period of weeks to a month may suggest infectious, neoplastic, or metabolic etiologist of a dementia.
1.9.2 General neurologic examination

The remainder of the neurologic examination should be conducted paying specific attention to focal upper motor neuron findings, (which may implicate other processes such as a vascular contribution) abnormalities in muscle tone, rapid alternating motions or tremor (which may indicate basal ganglia disease), signs of increased intracranial pressure such as papilledema or a peripheral neuropathy (which may implicate toxic or metabolic causes).

The neurologic examination should also include a general clinical medical examination of other organ systems.

1.9.3 Laboratory tests

About 5% of outpatients with suspected dementia had metabolic abnormalities which may have produced or contributed to the cognitive dysfunction. Various psychological tests are the following:

(a) *Mini Mental status examination (MMSE)*

This test concentrates on the cognitive aspect of a subject's mental functions, such as orientation, alternation, instant recall ability, short term memory, arithmetic ability and the ability to copy things. There are 30 items; each carries an answer is given one point. The scoring is by summing all the points, giving a range of 0 - 30. The validity and reliability of this test was well established and is commonly used as a screening test for cognitive impairment (Folstein et al 1975). It will take only about 10 minutes to administer this.

(b) *CAMDEX : Section B (Roth et al 1986)*

This test assesses a wide range of cognitive functions such as attention, orientation, memory, perception, language, calculation, praxix and abstract thinking. This instrument is
reported to identify even mild level of cognitive impairment. There are 57 items. The maximum score is 106. The suggested cut off score is 79/80.

(c) CAMDEX: Section H: (Roth et al 1986)

This is a structured interview regarding history and functional assessment with a relative or a care-giver who knows the patient well. By using this, it is possible to investigate the eventual development of difficulty with everyday life of behavioural and personality changes.

1.9.4 Discussion of diagnosis and formation of rapport with the family

It is best to be frank while discussing the diagnosis with the patient’s family. To cloak the diagnosis in euphemistic terms, or to be vague, may actually be counterproductive in the long term management of dementia. Although relatives should be informed that dementia is an irreversible process and that further decline is to be expected, there is little to be gained by a graphic description of the stages of decline and an enumeration of all the problems they may eventually have to face. Rather, one should adopt a ‘one step at a time’ approach and limit one’s focus to current and immediately expected problems. No matter how well prepared a family may be and no matter how compassionately this information may be transmitted to them, the time of the initial diagnosis is always one of great stress. The most helpful thing health care professionals can do at this point is to convey to patients and their families a firm intention to stay with them throughout the subsequent course of the illness and to help them cope with problems as they unfold. Not only does this lift morale, but it helps the professional enlistment the family in a joint effort to care for the patient. Indeed, it is only with the full participation of a family member or other responsible person that a moderately or severely demented patient can safely remain an outpatient. The absence of such a support system is an indication for admission to a long-term care facility.
1.9.5 Those whose lives it has clouded

Former President Ronald Reagan, Actress Rita Hayworth, Irish born Philosopher Iris Murdoch, Dutch Artist Willem de Kooning, Middle Weight World Champion Sugar Ray Robinson, the world renowned essayist and story teller E.B. White, Aron Copland, the famous composer of folksy American Jazz Swimmer Mihirsen, renowned poet Nissim Ezekiel are the unfortunate victims of dementia.

1.10 PHARMACOLOGICAL INTERVENTIONS IN DEMENTIA

Dementia is the acquired, impairment of intelligence, memory and personality (Lishman, 1978). Although therapies for dementia is chiefly psychosocial, it is increasingly being recognised that psychopharmacological nihilism in dementia is no longer warranted. A considerable body of research is available, laying down guidelines for the pharmacotherapy of dementia and suggesting experimental therapies as well as lines for further research.

1.10.1 General Principles in the Drug Therapy of Dementia

1. *Treatment considerations*

* Treat the underlying disease process
* Treat the psychiatric symptoms
* Treat the cognitive deficits
* Treat the complications.

2. *Limiting factors in treatment*

* Vulnerability to drugs due to age
* Vulnerability to drugs due to concurrent illness
* Vulnerability to drugs due to central cholinergic impairment
Vulnerability to drugs due to peripheral organ senescence/disease.

3. Guidelines for treatment

* Use as few drugs as possible
* Use the lowest effective dose
* Prefer drugs with short half lives
* Use divided doses instead of a single, daily dose.
* Avoid drugs that sedate
* Avoid drugs with anticholinergic action
* Identify the drug / dose/schedule with optional benefit - risk trade off.
* Involve relatives in drug therapy supervision.

In considering drug therapy, there are four aspects of dementia that the clinician must keep in mind; the underlying disease process, the psychiatric symptoms, the cognitive deficits and the complications of the illness.

Age and illness are two important limiting factors in treatment - both limit the number, choice and dose of drugs to be administered as elderly, demented patients are especially sensitive to all drug effects, whether favourable or adverse.

1. Several factors underlie age-related vulnerability to drugs. In the elderly body weights on average low during distribution volume is therefore restricted, and for a given dose, drug levels are higher.

   Poor nutrition and hepatic senescence may result in lower plasma protein levels. In consequence, free drug levels are higher.
Elderly persons tend to have less body fat. As most psychotropic drugs are strongly lipophilic and get deposited in lipid reservoirs, in the elderly less of such lipid storage takes place and a larger proportion of a given dose of drug remain in circulation.

In the elderly hepatic metabolism and renal excretion decrease in efficiency even if no disease of these organs actually exists. Drug half-life is consequently increased.

Brain volume decreases with increasing age, particularly when dementia is present. Neuroreceptor number and density correspondingly decrease. Hence, a given dose of psychotropic drug produces a longer effect on target cerebral structures.

One net effect of these age-related influences is that lower initial and maintenance doses are required to produce a desired blood level and a desired therapeutic effect; that adverse effects appear at lower doses of the drug, and that duration of drug effect is prolonged, necessitating wider spacing of doses.

2. Illness-related vulnerability to drugs also needs to be kept in mind; medical illness is common in the elderly. Such illness may be causal to (e.g. cerebrovascular disease) independent of (e.g. viral hepatitis) or indirectly resultant from (e.g. malnutrition, pneumonia) the dementia. The medical illness will require treatment. Hence, the number, choice and dose of psychotropic drugs will be limited by the organs affected by the medical illness (because of possible impact on drug metabolism, excretion or effect) and by the concurrent medical therapy (because of potential drug interactions).

3. Central cholinergic vulnerability to drugs is of paramount importance. Drugs with anticholinergic effects can impair memory and produce agitation, confusion, disorientation and other indices of cognitive dysfunction. This is because cognitive - particularly amnestic processes are subserved by cholinergic neurotransmission in the brain; the cognitive dysfunction in dementia is believed to be due to compromised central cholinergic function.
Peripheral receptor/organ vulnerability to drugs is a function of both age and illness-related variables: disease-related changes make organs vulnerable to drug-induced adverse effects even at low circulating drug levels. Thus, for e.g. the elderly are more likely to develop dryness of mouth, blurring of vision, constipation, urinary retention etc. as peripheral, drug-induced anticholinergic adverse effects.

Keeping the above in mind, general principles of therapy are enunciated as follows:

a. Use as few drugs as possible: This lessens the risk for confusion about medication schedules, for drug adverse effects and for adverse drug interaction.

b. Use the lowest effective dose, or the dose with the most favourable benefit adverse effect trade off. The need for keeping dose low has already been discussed.

c. Prefer drugs with short half-lives.

d. Use divided doses whenever possible. This attenuates peaking of drug levels (and hence adverse effects associated with peaking - problem in the elderly) and produces a smoother response.

e. Avoid sedating drugs (unless necessitated by the psychiatric state), particularly in the daytime. The patients are already cognitively compromised; sedation will further impair cognition.

f. Avoid drugs with anticholinergic action as these aggravate the cognitive deficits of dementia, and as these are also associated with peripheral intolerance.

g. Involve the relatives in (supervision of) drug therapy and provide detailed, written instructions to ensure accurate adherence to treatment regime. The patient, by virtue of his illness, cannot be relied upon to handle his medication himself.
1.10.2 New understanding of the pathological process and Possible avenues of treatment

As mentioned before, Alzheimer’s disease (AD) results mainly in the deposition of abnormal amounts of Beta Amyloid Protein (BAP) which form the core of the characteristic senile plaques. It has now been found that the Beta amyloid protein (BAP) is cleaved from a mother protein, Amyloid precursor protein by a scissor enzyme Gamma Secretase. This is a normal process that occurs in all cells, but in Alzheimer’s disease this phenomenon is exaggerated. Moreover, the cleavage takes place at a different site, resulting in the formation of an abnormally long Beta amyloid protein (BAP) containing 42 Aminoacids (as compared to the normal sequence of 40 aminoacids). This abnormal Beta amyloid protein (BAP) tends to elicit an immune response from surrounding lymphocytes resulting in the release of prostaglandins that can also damage innocent cells nearby. Specific inhibitors of Gamma secretase would offer a method of reducing the abnormal formation of Beta amyloid protein (BAP).

The normal neuron has a cytoskeleton that consists of parallel rows of protein strands that are held in place like the sleepers of a railway track by special protein molecules called tau and ubiquitin. In Alzheimer’s disease some damage occurs to the protein, resulting in their inability to hold the cytoskeleton in place. This lead to a distortion of the cytoskeleton, malformation of neurofibrillary tangles and neuronal malfunctioning.

It is still controversial what initiates the process. There has been a fierce debate between the Baptists (scientists who support the fact that abnormal deposition of altered Beta amyloid protein (BAP) is the primary process) and the Tauist (who claim that the formation of neurofibrillary tangle occurs first) some progress has been made in the resolution of this controversy because of the development of special genetically modified
strains of Labmice. One strain has an abnormality that mimics human Alzheimer’s disease, in that there are usually large amounts of Beta amyloid protein (BAP) deposited in their brains. Recently a vaccine has developed that seems to halt the deposition of Beta amyloid protein (BAP) in these mice and even reverse the process. Human trials are presently underway and this offers promise for essential control and cure of Alzheimer’s disease.

Similarly, strains of mice have been developed that mimic the formation of neurofibrillary tangles. Once again, cross breeding of the two strains has led to the presence of both Beta amyloid protein (BAP) and neurofibrillary tangles, providing an animal model of the disease. This is a great stride in experimental work, providing a platform where Alzheimer’s disease can be experimentally studied and newer drugs can be tried out in animals before being extended to man.

Derangement of various neurotransmitter systems especially Acetylcholine is a hallmark of the disease. Tremendous advance has been made in the understanding of the basic mechanism of neurotransmitter function, and specific method of correcting the malfunctioning in various diseases. So far, the mainstay of drug treatment of Alzheimer’s disease has been the cholinesterase inhibitor, which prolong the effect of the depleted acetylcholine, partially reversing the malfunctioning. Newer and better ChE inhibitors have been developed, which have more specific action and fewer side effects. Rivastigmine, Galantamine are some drugs that show promise. Other drugs like special prostaglandin inhibitors (Cox-2 inhibitors) may block the toxic effects of the immune reactions elicited by abnormal deposition of Beta amyloid protein (BAP). This would probably control the damage to normal cells in Alzheimer’s disease. Similarly, some newly discovered Nerve growth factors may help in restoring some of the damaged synapses and even replication of new cells to replace the dead or dying cells of Alzheimer’s disease.
Eventually, the promise of complete cure lies in the understanding of the basic genetic defect that results in the formation of abnormal proteins. The recent discoveries of the human genetic sequence will go a long way in the unravelling of these mysteries and would result in total cure of Alzheimer's disease in the not so distant future.

1.11 AYURVEDIC CONCEPTS IN THE MANAGEMENT OF DEMENTIA

Alzheimer's disease (AD) is a progressive degenerative brain syndrome. Incidence and prevalence of Alzheimer's disease is skyrocketing globally. No foolproof remedy is available in the cosmopolitan system of medicine. According to Ayurvedic approach, the concept of mind and mental health is unique in many senses. Manas (mind) is the connective link between the Indriyas and Atma (the soul, which is the seat of knowledge/wisdom). So Manas is attributed with various faculties of Dhee, Dhruthy and Smruthy. The Manas is thought to execute its functions in the body by travelling through specific channels - manovahasrothas. It is the function of Vatha dosha to initiate and maintain the free movement of Manas through Manovahasrothas. Old age is the period where there is a depravity of vatha dosha naturally. This Vathadosha due to its abnormal functioning can bring about problems with Manovahasrothas. It can also cause deterioration in the quality as well as the quantity of the dhathus of body. It is these two factors together, i.e., Dhathukshaya and affliction of manovahasrothas, which precipitates various malfunctioning of dhee, dhruthy and smruthy. For managing a clinical condition like Alzheimer's disease, the basic approach is to normalize Vatha, reestablish proper functioning of Manovahasrothas and to compensate dhathukshaya. The Rasayana Chikitsa offers great potential in such cases.

In India Ayurvedic physicians have used various products for centuries in the treatment of memory disorders. Brahmi and Ashwaganda are well known ingredients of many ayurvedic medications. Shilajit an extract from rocks has also been used. However,
none of these preparations have been subjected to rigorous clinical testing. Brahmi is already being marketed widely as “memory plus” despite the lack of scientific evidence of its efficacy.

1.12 NON-PHARMACOLOGICAL MANAGEMENT OF DEMENTIA

Clinical symptomatology in Alzheimer’s disease can be divided into three primary domains, i.e., cognitive, functional and behavioural. Cognitive deficits include impairment in memory, thinking, language, comprehension, calculation, learning capacity and judgement. As per definition of dementia impairment in cognitive functioning should be severe enough to affect activities of daily living. A number of behavioural problems also occur in association with these changes.

At the moment there is no curative treatment for Alzheimer’s disease. So the treatment is aimed to improve the quality of life of the patient and the caregivers and to reduce caregiver’s distress. In order to achieve these aims we need interventions at different levels ie. individual, family and community.

1.12.1 Memory loss in Dementia

Recent memory impairment is characteristic of dementia. Most people with dementia are likely to remember the distant past more clearly than what has occurred more recently. Long-term memories are comparatively preserved during the early stages. However these long-term memories also will eventually decline.

People with dementia will have problems in acquiring new information and there may be loss of sense of time. They may eventually lose their ability to recognise people, places or things. How can we help these people with memory problems? Techniques like memory aids, reality orientation and reminiscence therapy may be helpful especially during the early stages.
1.12.2 Memory aids

Memory aids such as lists, diaries and clear written instructions can be helpful if the person is willing and able to make use of them. Displaying large clearly labelled pictures of relatives will help the person to keep track of who is who. Labelling the doors of the rooms with words and bright distinctive colours can be helpful. Memory aids will not be so useful in the later stages of Alzheimer’s disease.

1.12.3 Reality orientation

Reality Orientation is a technique that is widely applied all over the world. There are two approaches to reality orientation.

Class room reality orientation involves intensive stimulation for periods varying from 30 -60 minutes a day. During these sessions the patient is given orientation to the day of the week, the month, the day of the month, the year, what the weather is like and so on. Reality Orientation (RO) board, written instructions, clocks, calenders, maps and posters can be used to enhance reality orientation. The other form of reality orientation has been called 24-hour reality orientation. This usually takes place in a hospital ward or residential home. Instead of being presented with an intensive information session, the subjects are oriented in their relevant every day activities throughout the day.

1.12.4 Reminiscence therapy

Reminiscence is looking back over our lives, recalling past memories of people, places and events. Our life experiences influence our personality; therefore, our memories give us a sense of who we are.
A person with dementia begins to lose their memory. In the early stages short-term, memory is affected more than long term, or distant, memory. At the late stages of dementia both long and short-term memory will be seriously affected.

It is the duty of the carers to encourage people with dementia to talk about and share their memories and to help them enjoy these memories. Even for people in the late stages of dementia it is often possible to find some cue, a song of a picture, which will give them pleasure.

Reminiscence activities include Conversation, Reading, Singing, Cooking, Discussion, Drawing, Writing, Question cards, Life story book, Smelly box and Rummage box etc.

1.12.5 Behavioural therapy

Patients with dementia may exhibit a wide variety of behavioural disturbances, including depression, agitation, hallucinations and delusions, anxiety, violence, sleeplessness, and wandering. These behaviours can cause considerable distress to family members and professional caregivers. Non-pharmacologic approaches to behavioural problems should be tried before resorting to drug therapy. For example, treatment for depression may include encouraging simple activities that promote success and a sense of usefulness (setting the table, gardening, cleaning). Arranging comfortable social gatherings and encouraging activity can also help improve the mood. Sleep disturbances in the patient that keep the caregiver awake at night can be particularly problematic. Keeping the patient active during the day with exercise and avoiding naps can minimize wakefulness at night. Encouraging the patient to use the bathroom before bedtime may help prevent nocturia and using a night-light can help prevent nocturnal confusion.
Wandering poses a risk of physical injury to the patient and may be due to restlessness, confusion, boredom, or need for exercise. This needs to be tackled sometimes with medication.

At some point, most Alzheimer’s dementia patients experience agitation, and some experience hallucinations and delusions. Agitation can be managed by providing a calm, well structured, and predictable environment, as well as outlets for nervous energy. In many instances, a stimulus in the environment triggers the anxiety and agitation. Although the cause of anxiety may not be immediately apparent, identifying and eliminating the cause is the single best treatment. With patients who develop hallucinations and delusions, the caregiver should avoid confrontation, especially if the delusion poses no danger. Simple, calm reassurance is often helpful.

In general, avoiding confrontation is the best road to success for managing problematic behaviours.

1.12.6 Social interaction

Relatively simple environmental changes will increase the amount of interaction. Patients talked much more to each other at mealtimes if their chairs were grouped around tables- instead of being in lines along the walls. Other studies have attempted to increase social interaction in a small group setting. Using behavioural methods such as prompting, social reinforcement and positive feedback helped increase social interactions. Having visual aids or other prompts is important in eliciting social behaviour to be reinforced. Good conversation stimulators include music, pets, children and reminders of younger days.
1.12.7 Domiciliary care

Most of the persons with dementia live at their homes with their family. Many a times the support given by the family may be inadequate or inefficient due to the lack of understanding of the disease process, inability to deal with the behavioural problems associated with dementia or due to inter-personal problems or caregiver’s distress. Trained manpower is essential to look after the persons in the community. Imparting training to health workers to deal with these problems will be very useful.

1.12.8 Day care

The daily care provides respite to the caregivers and rehabilitation to the patient. The programme is very helpful to those families where all the family members are working or those who are unable to take care of the patients due to family disharmony or lack of personnel. Regular attendance in these programmes enables close monitoring of the physical and psychiatric status of the patients so that early intervention and treatment is possible.

1.12.9 Family intervention programme

Dementia does not simply affect the person who has it. It profoundly changes the lives of those family members who are close to that person. Care giving in dementia is time consuming, frustrating and a demanding task which can leave the caregiver, frustrated, depressed angry and alone.

Psychotherapeutic intervention with family members is a critical aspect of the treatment. Psycho education is the most important component of the programme. Providing information about the nature, course and prognosis of the illness help the caregivers to lowers their expectations about the patients, which in turn reduces the
intensity of frustration. The programme is aimed to change the perception of the caregiver, to enhance problem-solving skills and to provide support.

1.12.10 Self help group - caregiver’s meeting

Caregiver’s meetings provide support in a group setting. Groups allow for the ventilation of feelings and the development of a group process. It provides opportunities for caregivers to come together, empathise with each other, share their problems and solution, and acknowledge and affirm each other’s care giving efforts. Living with and caring for a person with dementia demands newer and newer coping strategies from the caregiver. Caregiver’s meetings provide an opportunity to learn how to cope better as demands are changing. What can a support group do?

* It supports relatives or friends so that they can cope more easily.

* Common experience, problems and solutions.

* Works on principles of sharing and co-operation.

* An outlet of pent-up emotions.

* Reduce feelings of helplessness and despair.

* Provide a chance to discover that their situation is not unique.

* To exchange ideas and disseminate information

* Improve problem-solving skills.

* Offer advice and support

* A social event - a break for the carer.
1.13 IMPACT OF DEMENTING DISEASE ON CARE-GIVING FAMILIES

It is commonly held that caring for an elderly person who is mentally ill is far more of an emotional drain than caring for a person with physical disabilities (Poulshock & Deimling 1984). This is largely because the disabilities of the dementia sufferer have more far reaching consequences in terms of changes in the care giver's lifestyle and also because of the disruption of the relationship (Morris et al. 1988). Family members are quite often devastated, demoralized angry or guilt ridden by some aspect of the illness. Quite often they fear that they may have caused it or else have brought the patient to medical attention too late. They may feel frustrated and angered by the behaviour of the ill person, by the lack of support from other family members and even at fate for having dealt them such a cruel blow.

Considerable research has gone into reviewing the impact of care giving on care givers. These studies are all in agreement over the fact that care givers experience considerable burden and emotional disorder. According to Morris et al. (1988) there are many of factors that affect the emotional well being of the care giver namely his/her attributions and coping strategies, the quality of the care givers relationship with the dementia sufferer, the family and the social context.

Studies conducted by Page et al (1985), Coppel et al (1985) and others revealed that care givers were more likely to be depressed if they felt a loss of control over their spouse's behaviour and if they felt unable to cope with the impact of care giving. They were also more depressed if they were dissatisfied with their ability to cope with changes in their daily lives and if they thought that they would not be able to cope in the present or future. Studies have also revealed a significant association between depression and the
ability of the care giver to cope with their own emotional reactions. These associations extended beyond depression to include a level of strain experienced by the care giver.

The ability of patient to cope with the impact of care giving may depend in part on the amount and quality of formal and informal support that the care giver receives. Care givers who have a larger network of social support tend to feel less need of formal support. Formal support such as that received by visits from community nursing home help should alleviate the degree of subjective burden. But this concept has not really caught on, in our society. There are a small group of affluent care givers who may be able to afford a nurse but the bulk of the population cannot. Institutions for the care of dementia patients are few and far between. Most of them are essentially institutions for the care of the aged, which are not really equipped to deal with the problems posed by dementia sufferers.

1.14 PSYCHOSOCIAL PROBLEMS OF CARE GIVERS

Family members experience many negative feeling as they care for a person with Dementing illness. Some feel sad and discouraged. Some feel angry guilty or hopeless. Usually a female relative of the sick person assumes the lead role in care giving. According to Morris et al (1988) there are many factors that affect the emotional well being of the care - giver namely his/her attributions and coping strategies, the quality of care - givers relationship with the Dementia sufferer, the family and the social context.

To a large extent the type of pre - morbid relationship the care - giver had with the dementia sufferer determines his/ her sense of involvement with the patient. A warm loving relationship invariably produces a deeper sense of commitment to caring. However such a close relationship is also significantly correlated with poorer mental health of the care giver as it reflects the emotional involvement of the care - giver with the sufferer and his illness (Gillhooly 1984). Poor previous relationship results in extra tension, impaired partner become resentful and hostile when dependent on caregiver (Morris et al 1988).
Female caregivers were found to have much poorer well being as compared to males, probably because their sense of involvement was more. Men on the other hand were able to distance themselves from the problem and were less socially isolated.

The emotional reactions experienced by the primary caregiver may be considered in detail.

(a) Anger

It is understandable for the primary care-giver to feel frustrated and angry; angry that this has happened to her, angry that she has to be care-giver, angry with others who do not seem to be care-giver, angry with others who do not seem to be helping, angry with the impaired person for his irritating behaviours, angry that she is trapped in the situation.

(b) Embarrassment

Often the behaviour of a person having a dementing illness is inappropriate and awkward. So family members feel embarrassed, strangers do not often understand what is happening.

(c) Hopelessness

It is common for care-giver to feel hopeless, weak or demoralised in the face of a chronic dementing illness.

(d) Guilt

It is quite common for care-giver to feel guilty about the way they treated the person in the past; about being embarrassed by the person’s odd behaviour, about losing their temper with an impaired person, about not wanting this responsibility; about considering placing the person in a nursing home and for many other reasons. Some trivial, some important.
(e) Depression

Studies conducted by Pagel et al (1985) Coppel et al (1985) revealed that caregivers were more likely to be depressed, if they felt a loss of control over their spouse’s behaviour and if they felt unable to cope with the impact of care-giving.

Families of the chronically ill often feel sad, depressed discouraged or low day after day, week after week. Depressed people may also feel anxious nervous or irritable. A chronic dementing illness makes its toll on emotions of the care-givers and provides a real reason for feeling low.

(f) Isolation

Sometimes the primary care-giver feels that she is facing the situation alone. The feeling of being alone is not uncommon when people are facing a dementing illness. Many carers feel extremely isolated when the immensity of the task ahead dawns on them. Some have struggled on for years before realising that many people are in a similar position as themselves. The isolation is not just psychological, but also physical. Some sufferers with dementia require almost constant attendance, twenty-four hours attention. This gives little opportunity for a carer, particularly an elderly spouse who may have physical problem of his or her own, to get out and meet other people. This situation is often compounded by embarrassment at the behavioural abnormalities that so frequently occur.

(g) Fatigue and illness

Many people looking after an older person with Dementia are themselves elderly and suffer from chronic medical condition of one sort or another. If on the top of these they also have to cope with the mental and physical demands of caring for someone with dementia, it is possible that their own illness may be aggravated. Many have to struggle on despite being unwell themselves. There is also possibility that a care giver may fall without
losing consciousness, but unable to summon help. A person with dementia may well be incapable of helping in this circumstance and can sometime make matter worse.

(h) Grief and Bereavement

As dementing illness progresses, relatives and to a lesser extent friends have to come to terms with the loss of someone they have. This is particularly painful when the sufferer is unable to communicate with, understand or recognise the carer. This sense of loss is very difficult to cope with sometimes and the long - drawn out grieving process may affect the pattern of bereavement when the sufferer eventually dies. With a progressive illness like dementia, the grief can get worse as time goes on and very often death is a merciful release from this type of emotional turmoil, just as it is from the physical burden and the distressful existence of the sufferer.

(i) Loneliness

Many care givers withdraw from the society and are confined in and around their homes with the person with Alzheimer’s disease. Being a care giver can be lonely. He or she may have lost companionship with the patient and lost other social contacts due to the demands of being a caregiver. Loneliness makes it hard to cope with the problems of care giving.

(j) Family Problem

Coping with dementia can generate two different types of family problems. The first is the stress that can be caused by the demands that the disease makes on the carers and often their children. The second connected with the first, is the ill-feeling that can sometimes be fostered within families because one or two members feel that they are taking most, if not all, of the responsibility and providing the greater part of the care.
1.15 EFFECTS ON DEMENTIA ON CARE GIVERS

Mental health professional tends to underestimate or ignore altogether - the stresses under which relatives of the demented operate. These stresses are both emotional and material - emotional, in that they are in continued close contact with a near and dear one in obvious distress and whose suffering they are unable to alleviate, and material, in that considerable time, energy, and money and perhaps other resources are spent without obvious gain.

These stresses cannot be avoided. What can be done however is to reduce their impact? This can be done in many ways. Stage - by- stage education of the relatives about the current situation provides them with time and opportunity to face eventualities. Group sessions between a family and the therapist, with the therapist providing active support; reduce the family’s frustration and guilt at being unable to help. Relatives’ groups provide a forum for ventilation, sharing of experiences and mutual support; it is a powerful reassurance for a family to realize that it is not alone in the problems that it faces, or in its frustration at being helpless, or even in the often unacknowledged resentment and hostility that it experiences towards the demented member.

The primary care - giver is the person and most heavily affected by the process of care - giving. As the primary care - giver is often a female; she may also have to take the responsibility of looking after young children and her husband. Sometimes the negative family dynamic prevent other female relatives from giving a helping hand to the primary care giver. So in many families with a demented elderly the plight of primary care - giver is indeed pathetic. It also needs to be mentioned that apart from the primary care - giver, every member of the family is affected by the dementing illness.

Modernisation and the trend towards urbanisation and industrialisation are having its impact on the Indian family structure. The joint and the extended family system, which
was the norm, are now breaking up in the face of an increasing trend towards urbanisation. Whole families are splitting up with the sons and daughters moving out to the big cities and towns in search of better quality of life. Under these circumstances the demented persons who had always been the head of the family are being left with virtually none to care for them. Therefore pressure for an increased level of community support is mounting. While it is true that compared to the west, the Indian family is far more cohesive, this must not prevent policy makers and planners from waking up to the fact that changes are taking place in Indian family and measures need to be instituted now as to avoid serious problems in future.

1.16 CONCLUSION

Dementia is an illness that affects not only the affected individual but the entire family. The plight of demented elderly and their families are very serious. The condition will become much worse in the next couple of decades with the phenomenal increase in the elderly population. The most affected one in the family due to dementia patient would, be the care-giver. The care-giver can develop many physical and psychological problems when they experience severe stress day in and day out. As a reaction to chronic heavy burden, they may develop, “burn-out” which can hamper the quality of life of the patient and the health of the primary care-giver. The concept of expressed emotion is operative in much care-givers dementia sufferers’ relationships. The degree of it is related to the pre-morbid relationship between the carer and the person with dementia as well as with the stage of dementia.