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ALZHEIMER'S DISEASE : Caught between life and death

Marie was blissfully unaware that a disease like Alzheimer's even existed. Except in rare moments of enlightenment, she was not even aware that she was ill. When her daughter last met her in Canada, she was 68, and in perfect physical and mental condition. Ten years later, she could not recognise her daughter, kept suspecting people of trying to rob her jewellery and, minutes after being fed her dinner, would forget that she had eaten.

"Alzheimer's disease (AD) is the most common cause of dementia in people above the age of 50", states clinical psychologist and psychotherapist Dilip Panikker, who works with the Alzheimer's Project at the Holy Family Hospital in Mumbai. Of the cases brought to the clinic, over half of those with dementia are found to suffer from Alzheimer's disease. AD usually strikes the elderly, but in cases of pre-senile dementia can start as early as 40. It is characterised by a decline of mental and physical functions, finally leading to death in 5 to 15 years.

Often mistaken for madness or simply, old age, families are reluctant to talk about the disease as AD carries with it the stigma of mental illness, and a possibility of it being hereditary. AD destroys the brain cells and over a period of time, robs sufferers not only of their faculties, but even their dignity, till death comes as a relief. AD is tragic, not because it causes untimely death, but because it involves mental deterioration and increases dependency on others. Like the one-legged Captain Ahab in 'Moby Dick', AD sufferers, like Marie, walk a thin line that straddles life and death.

Its most devastating effect, however, is on the patient's family. Caring for an AD victim causes considerable emotional and economic hardship for the care givers, who are usually relatives. The long period of deterioration can be extremely demanding for even the most devoted care giver as many patients need round-the-clock care. While care givers find it easier to accept that their parents or other elders have Alzheimer's, it is much more difficult when the sufferer is a spouse. The final stages when the patient has no control over vital functions, are especially taxing. Lena Tavares of the Alzheimer's and Related Disorders Society of India (ARDSI), estimates that the cost of caring for a patient, with medical tests and recurring costs for symptomatic treatment can range from Rs. 10,000 to 50,000 per month. Just the incontinence pads, used to avoid repeated changing of bedcovers, are priced at Rs 95 for a pair. The tests required for diagnosis of AD - physical, neurological as well as psychiatric - also place a tremendous financial burden on most elderly people and their families.

The Alzheimer's Project at the Holy Family Hospital conducts the requisite tests for a nominal charge, but awareness of the disease is poor, even among the medical fraternity.

Besides the financial burden, care givers and family members suffer from isolation, depression, and exhaustion, resulting in increased health problems. ARDSI, the first organisation in India to create awareness about Alzheimer's, has a support group for the care givers of Alzheimer's patients. The Alzheimer's Disease Research and Services Project at the Bandra Holy Family Hospital also has a support group which meets every Thursday afternoon. Support groups help caregivers to share experiences, information and coping strategies, and ventilate in the presence of strangers. With the co-operation of Alzheimer's Disease International and the WHO, the Project has issued a booklet which presents useful information on how to cope with the disease, and on how to set up self-help and mutual support activities for families affected by AD and other dementias. Providing respite for care givers, to allow them to attend to their personal and individual needs, is an issue that is yet to be tackled. The Holy Family Hospital plans to start a respite centre for caregivers, but funding is hard to come by.

While family support is customarily available in our country, Prof. Dilip Panikker notes that people who attend the support group usually belong to a nuclear family. With the breakdown of the joint family, the support base offered by the family unit is being eroded. Old people often lack emotional support, and when made vulnerable by a disease like Alzheimer's, can often end up at the mercy of unscrupulous relatives who take advantage of their impaired decision-making capacity.

Unable to cope with their special needs, behavioural disturbances and sometimes violent behaviour, old age homes are not willing to accept patients with Alzheimer's. With no social security, no respite centres for the care giver, no Alzheimer's / dementia specific homes, and lack of political interest in a segment of the population seen as unproductive, sufferers of Alzheimer's, and their families face a bleak future. Although patients with dementia, need more care and attention, meeting their needs does not seem to be one of the government's priority areas.

Home care is still the best option, and though providing better home care might entail re-orienting medical services, it will provide a cheaper and more practicable alternative to hospital care for the estimated three million Alzheimer's patients in India. As we move into the future and life expectancy increases, the segment of the population over the age of 65 will continue to increase and we will see a large increase in the number of AD sufferers. Perhaps for this very reason we need to ensure that the dying can depart with the dignity and peace they deserve. For in sharing the process of dying, we enhance our own sense and understanding of living.

ALZHEIMER'S DISEASE : The Facts

Named after the German physician who first described the disease in 1906, Alzheimer's disease is a brain disorder and not a normal consequence of ageing. In AD, a gradual loss of nerve cells in the brain occurs. Patients suffer from severe memory loss and an inability to function independently. The most common of all dementias, AD occurs primarily in the elderly, and affects more women than men. At present, two types of Alzheimer's dementia are thought to exist. **Sporadic AD** or senile dementia, is the more common type. **Familial AD**, which is rarer and appears to have a strong genetic component, can occur at an early age, as well as later in life.

Diagnosis

Researchers do not know the cause of Alzheimer's disease, but various hypotheses are being explored. Evidence points to the degeneration and death of nerve cells in the areas of the brain responsible for thought processes, memory, and speech. Examination of AD brains reveals that some brain cells in these regions are filled with tangles of protein fibres, called "neurofibrillary tangles", as well as clumps of degenerated nerve cell extensions, called "senile plaques". Both, damage to nerve cells and deficiencies of brain chemicals - called neurotransmitters - occur in AD. Patients have reduced levels of **acetylcholine** - a chemical involved in memory processing - and other neurotransmitters.

AD is difficult to diagnose in its early stages. General ageing, other types of dementia, several medications, psychological problems and systemic illnesses can all lead to symptoms similar to the early symptoms of AD. Hence AD is diagnosed by eliminating other causes of dementia. AD characteristically involves changes in memory. Diagnosis of AD with certainty can only be ascertained after death, by an autopsy, when pathologists have examined brain tissue samples for the characteristic signs of damage.

The inability to diagnose early AD makes timely intervention and treatment difficult. Researchers at the Harvard Medical School detected a dramatic difference between patients with AD and healthy individuals, when their eyes were treated with an acetylcholine-blocking drug. The pupils of AD patients were found to dilate by 13 percent or more, while those of normal individuals did not dilate. This new 'pupil test' could be used to diagnose AD even before it can be detected by current methods. However the apparatus for testing is extremely expensive.

Disease Progression

When people are diagnosed with probable AD, they generally pass through a steady continuous progression of the disease. In the early stages, subtle personality changes occur such as social withdrawal and apathy, often noticed only by family members. The patient is usually aware of memory

lapses, and may become anxious and irritable as a result. Mild language disturbances may also appear. These changes can also occur during normal ageing as a result of medication, personal losses etc.

As the disease progresses, the patient tends to get disoriented and begins to wander. Sleep disturbances occur. The patient becomes progressively unable to reason or to evaluate a situation. Speech impairment, such as improper word placement, becomes more frequent. The patient displays general difficulty in conversation, and may repeatedly ask already answered questions within a very short time period. The ability to perform simple acquired skills, such as basic arithmetic and typing, is reduced and eventually lost.

In later stages of AD, the patient's former personality is completely lost. The patient is often not able to recognise close relatives and is unable to hold a simple conversation. The patient becomes totally dependent on caregivers and needs constant supervision. In the final stages, the patient can become incontinent, and suffer complete dementia, cerebral attacks, and coma before death. Death usually results from secondary infections such as pneumonia.

Treatment

Alzheimer's disease cannot be cured or prevented. At present, only the symptoms of AD can be treated, and even this treatment is of limited value. Treatment of AD focuses mainly on the symptoms of memory loss and disorientation, and is directed at increasing acetylcholine levels in the brain.

AD is irreversible, and no currently known drug can halt the progression of AD. Drugs like **tachrine hydrochloride** (COGNEX) and **donepezil hydrochloride** (Aricept) can slow down the course of the illness and improve cognitive performance in the early stages by increasing the availability of acetylcholine to the brain cells. However, these drugs are not yet available in India.

Other causes of dementia

Several conditions can lead to dementia, and they must be ruled out before diagnosing AD. **Multi-infarct dementia** (MID) is the result of several strokes, usually caused by arteriosclerosis. Mental deterioration in MID patients usually proceeds in abrupt intervals in contrast to the steady decline observed in AD. **Parkinson's disease** is similar to AD, because it involves low levels of a neurotransmitter - dopamine - and causes degeneration in certain areas of the brain. Patients suffer from tremors, muscular tenseness and slow speech. A third of Parkinson's patients eventually also develop AD. **Huntington's disease** is a rare and inherited form of dementia, and is characterised by irregular, involuntary movements, depression and memory problems. **Creutzfeldt-Jakob Disease** (CJD), - also called mad cow disease - is rare and leads to dementia, bizarre behaviour, and lack of co-ordination. It appears to be transmitted by an infectious agent and death usually occurs within a year of diagnosis.