



**World Health
Organization**

Regional Office for
South-East Asia

**ALZHEIMER'S
DISEASE:**

**The Brain
Killer**



when **old**
age becomes
a **disease**

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Paintings on pages 12 and 45 are part of a WHO-sponsored global school contest on mental health for children aged 6-9 years (both paintings by Dhruv Suri).

ALZHEIMER'S DISEASE: The Brain Killer

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Message from the Regional Director

Populations of Member Countries of the World Health Organization's South-East Asia Region have suffered for ages from many communicable diseases. While some of these have been successfully controlled, others continue as serious public health problems. However, recently, it has become increasingly clear that noncommunicable diseases, including mental and neurological disorders, are important causes of suffering and death in the Region. An estimated 400 million people worldwide suffer from mental and neurological disorders or from psychosocial problems such as those related to alcohol and drug abuse. Our Region accounts for a substantial proportion of such people. Thus, the Region faces the double burden of diseases – both communicable and noncommunicable. Moreover, with the population increasing in number and age, Member Countries will be burdened with an ever-growing number of patients with mental and neurological disorders.

As Dr Gro Harlem Brundtland, the Director-General of the World Health Organization says, “Many of them suffer silently, and beyond the suffering and beyond the absence of care lie the frontiers of stigma, shame, exclusion and, more often than we care to know, death”.

While stigma and discrimination continue to be the biggest obstacles facing the mentally ill, inexpensive drugs are not reaching many people with mental and neurological illnesses. Although successful methods of involving the family and the community to help in recovery and reduce suffering and accompanying disabilities have been identified, these are yet to be used extensively. Thus, many population groups still remain deprived of the benefits of advancement in medical sciences. Dr Brundtland has said, “By accident or design, we are all responsible for this situation today.”

The World Health Organization recently developed a new global policy and strategy for work in the area of mental health. Launched by the Director-General in Beijing in November 1999, the policy emphasizes three priority areas of work: (1) Advocacy to raise the profile of mental health and fight discrimination; (2) Policy to integrate mental health into the general health sector, and (3) Effective interventions for treatment and prevention and their dissemination. The South-East Asia Regional Office of the World Health Organization is committed to promoting this policy.

Mental health care, unlike many other areas of health, does not generally demand costly technology. Rather, it requires the sensitive deployment of personnel who have been properly trained in the use of relatively inexpensive drugs and psychological support skills on an outpatient basis. What is needed, above all, is for all concerned to work closely to address the multi-faceted challenges of mental health.

Dr Utom Muchtar Rafei
Regional Director
World Health Organization
Regional Office for South-East Asia

Preface

Several centuries BC, Chinese, Egyptian, Greek, Indian and Roman healers were aware that advancing years and old age were associated with disorders of memory and other brain functions. In some cases, people who had previously been very intelligent and sensible started “behaving like children.” However, till the late 19th century, these symptoms were considered as a “part of old age.” It was only in 1906 that Dr Alois Alzheimer vividly described a patient with manifestations of dementia and since 1907, this common cause of dementia has been called Alzheimer’s disease.

Alzheimer’s disease is known to occur in all parts of the world where it has been systematically researched. It can affect anyone, regardless of caste, creed, race, socioeconomic group or gender. Even though it can affect anyone, yet nobody can be sure beforehand who it will affect. Unfortunately, myths and misconceptions about the disease are better known than facts. This often deprives patients of proper medical treatment, much to the detriment of both the patient and the family.

Some interesting and hopeful statistics were offered at the “World Alzheimer’s Conference - 2000” held in Washington DC, USA. It was said that the rate of occurrence of Alzheimer’s disease doubles every five years for those between 65 and 85 years of age but if its onset were delayed by five years, the number of cases worldwide would be halved. Thus, serious attention needs to be paid to the risk factors and preventive measures that may be taken to postpone the onset, if not prevent the appearance, of Alzheimer’s disease. Epidemiological data already suggest that certain communities in Asia and Africa may have a lower risk for Alzheimer’s disease compared to western countries. Researchers in India have suggested a gene-environment interaction in the causation of Alzheimer’s disease. Although genes cannot be altered, the environmental risk factors which interact with the genetic factors can possibly be modified, thereby reducing the risk. This promising concept must be pursued as it affords a ray of hope for the future.

Charles Colton, British churchman and writer (1780-1832) wrote: “Body and mind, like man and wife, do not always agree to die together.” We need to find out why the brain dies before the body, leading to the devastating disease called Alzheimer’s disease.

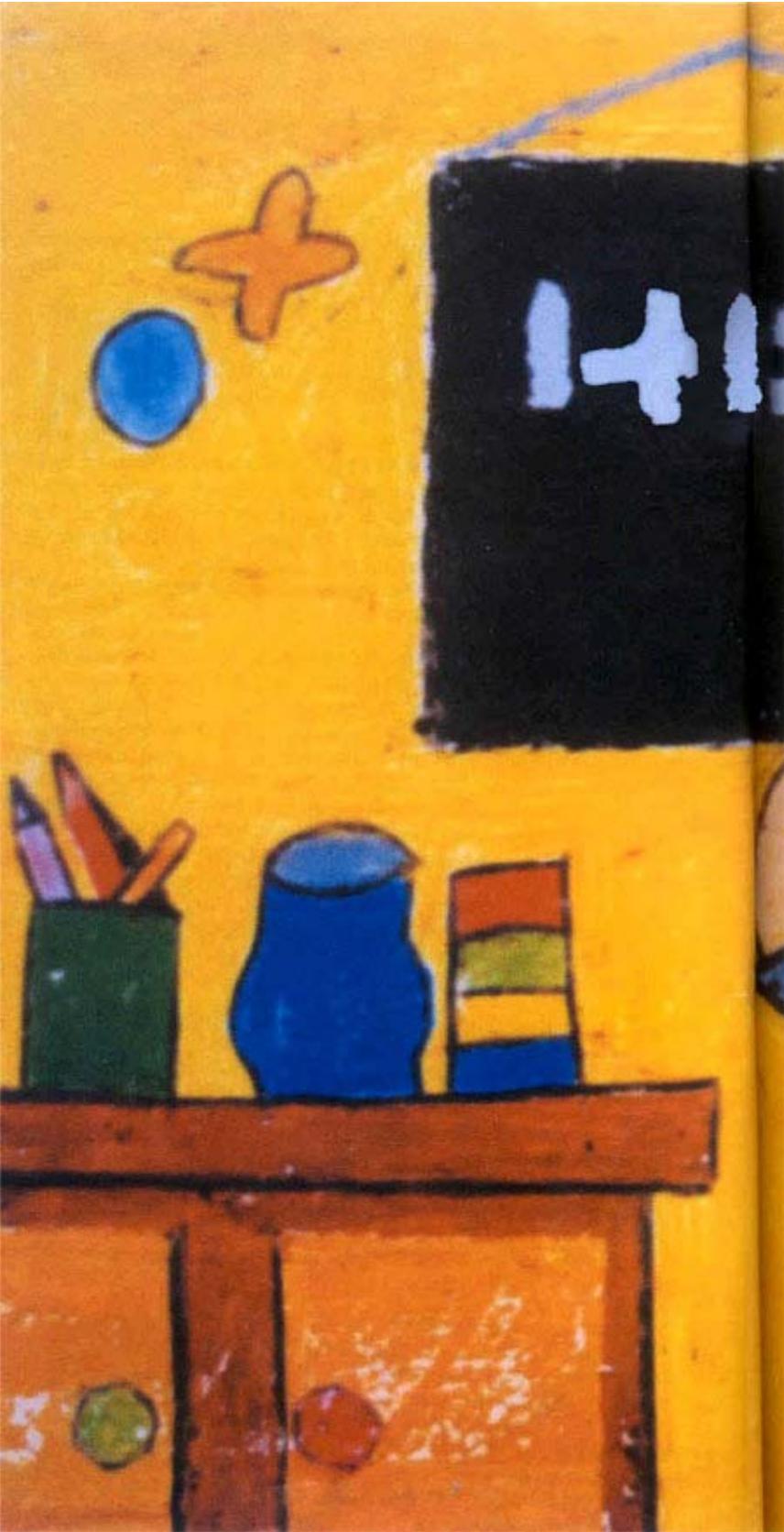
With increase in life expectancy, populations of Member Countries in the South East Asia Region (SEAR) will be increasingly faced with diseases which affect the older age group, such as Alzheimer’s disease. Thus it is time for governments to plan and address issues related to such diseases before they reach a crisis situation. The WHO Regional Office for South-East Asia is committed to assisting Member Countries in addressing the challenges of tackling these diseases.

This document, prepared by a panel of experts from the Region, provides valuable information for the lay person and policy-makers regarding the multifaceted aspects of “the brain killer disease” and what can be done to relieve the suffering of patients and their families.

Dr Vijay Chandra
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What if...

**...this were
the case with
you?**





Historical background

A rude shock...

A young man, Amit, was studying in the US. He had not been home for three years. He had heard that his grandfather was “growing old” but did not know that he was sick in any way.

The young man decided to visit his grandfather on his first day back home. He was met by the old faithful maid - the same maid who had helped bring him up. She hugged Amit, offered him a cup of tea and wanted to know all about him. Then she very quietly told him that his grandfather was not in the best of health but that she would call him. Mr B entered, shabbily dressed with his vest outside his shirt and looking frightened. He said that he had paid all his taxes and wanted to know why Amit had come to the house without an appointment. Mr B apparently did not remember Amit or that he was his favourite grandson. He kept calling Amit his brother. During dinner, the young man was surprised to see how his grandfather had aged: he was sloppy and made a mess of the food; slurped all the time; his previous impeccable table manners had disappeared. Finally, he got up after dessert, went to the corner of the room and relieved himself by ‘watering’ the potted plants. Amit was shocked.

Mr B soon went to bed. The maid of many years was embarrassed and unhappy. She told Amit that Mr B had been in this state for some twelve months. His memory, even for day-to-day things had faded. He could not remember telephone messages, would repeat himself incessantly, even demand breakfast and lunch a second and third time. He would try to take sexual liberties with her and, at the same time, accuse her of robbing him and letting thugs and crooks into his house. At times, when he was in a good mood, he would take her by the hand and introduce her to the fairies sitting on the window, then tell her to set the table and cook enough for the five fairies and themselves. His business affairs were in a shambles; yet, he tried to set up new companies and start projects which he promptly forgot. All in all, life was bad.

Amit was aghast. He took his grandfather to a doctor who referred him for special assessment by a team of doctors consisting of a neurologist, psychiatrist and psychologist. Certain tests were performed and a diagnosis of dementia due to Alzheimer’s disease was made.

Dementia, derived from the Latin word, [de-=out from + mens=the mind] means loss

or impairment of mental powers due to a disease. The word *démence* existed in the French language as far back as 1381. It is generally understood today as the “loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning”. This definition from the Diagnostic and Statistical Manual of the American Psychiatric Association of 1994 has a long and interesting history, which transcends generations and indeed civilizations.

The Egyptians and Greeks of the period 2000 - 1000 BC were well aware that advancing years and old age were associated with disorders of the memory. The Chinese used the words *Zhi Dai Zheng* for dementia and *Lao Ren Zhi Dai Zheng* for senile dementia which was described basically as a disease of old people characterized by muteness, lack of response and craziness. The Romans, i.e. AC Celsus and Claudius Galen of the first and second centuries AD, referred to chronic mental disorders known to produce an irreversible impairment of higher intellectual functions. The Ayurvedic physicians of India used the Sanskrit term *Smriti Bhransh* as early as 800 BC to describe loss of memory. Also, in India, the expressions *satar-batar* which literally translates to “turned 70” and another *sathiya gaya* which translates to “turned sixty” are used for old people. Research has indicated that these expressions are applied only to those older people

who show altered behaviour and loss of memory regardless of age. However, since this change most frequently happened in people at 60 or 70 years of age, the terms assumed a numerical connotation. In some parts of South India, the word *Chinan*, probably derived from the Dravidian languages, is used to refer to a condition associated with ageing, deterioration in memory, abnormal behaviour and occasional incontinence. While the concept of dementia in the aged is widely known in Thailand, Alzheimer's disease also known as *Roke Long* is not as well recognized.

The changes brought on the mind by old age have also been recognized in the past. William Shakespeare refers to them in his plays "As You Like It", "Macbeth" and "King Lear" - the last written about 1606, aptly describes what is known even today as dementia.



Act 4, Scene 7:60-70

LEAR:

"Pray, do not mock me:
I am a very foolish fond old man,
Four score and upward, not
an hour more nor less;
And, to deal plainly,
I fear I am not in my perfect
mind.
Methinks I should know you,
and know this man;
Yet I am doubtful: for I am
mainly ignorant
What place this is; and all the
skill I have
Remembers not these
garments; nor I know not
Where I did lodge last night.
Do not laugh at me;
For, as I am a man, I think
this lady
To be my child Cordelia."

CORDELIA:

"And so I am, I am."

Myths and misconceptions about Alzheimer's disease

Did you know that Alzheimer's disease can affect even the rich and famous?

Former President of USA, Mr Ronald Reagan, has Alzheimer's disease.

Many myths and misconceptions prevail about Alzheimer's disease. It is not only the common man but some physicians too who lack a proper understanding of this disease.

A minor decline in intellectual capability with advancing years occurs in most people. However, even when this progresses to the point of severe intellectual loss, clearly indicating a disease process, the family continues to accept it as a part of the ageing process and does not take their loved one to a doctor. There is a sense of fatalism and acceptance of ill-health in old age in the communities of South-East Asia. This is detrimental to the patients, as it deprives them of medical care, as well as to the family, as it suffers the consequences of a member's disease.

Myth:

This is senility, you can't reverse old age, so why go to a doctor?

Fact:

Alzheimer's disease is NOT "normal old age". Every elderly individual does not have this disease. Thus, it is important to be aware of the signs and symptoms which could suggest this disease and consult a qualified medical practitioner to assess your loved one.

Myth:

This is madness!

Fact:

Although, some Alzheimer's disease patients have behavioural symptoms, these are an integral part of the disease process. Under no circumstances should this be considered to be 'madness'. The patients are unable to control their behaviour and therefore, appropriate treatment is necessary. Although psychiatrists do treat Alzheimer's disease, every patient treated by them is not 'mad'.

Myth:

He is behaving like a child. I will teach him sense.

Fact:

Old age has been referred to in fiction as a "second childhood". There may be some elements of childish

behaviour in such patients but this is a superficial similarity. Family members and care-givers in their desire to be helpful, unknowingly try to “teach the patient to behave”. There are horror stories of patients being beaten and scolded as children are. Family members must realize that if the patients were capable of controlling their behaviour, they would have done so in the first place. Also, care-givers must realize that the ability to ‘learn’ new things is lost in patients. Thus, you cannot “teach him sense”; but appropriate treatment can help.

Myth:

What do you expect in old age? Such behaviour has to be tolerated.

Fact:

In general, society in South-East Asia respects the elderly and minor deviations in behaviour are tolerated. There is no cause for worry as long as it remains a ‘minor’ deviation from the normal. However, waiting for a crisis situation or for the disease to advance is undesirable. Both extremes should be avoided, i.e. perpetually worrying about every minor deviation in behaviour, or not to worry at all about major deviations in behaviour. A judicious middle path of concern for elderly family members is most desirable.

Myth:

He is possessed by evil spirits. I will take him to a sorcerer and get his evil spirit exorcised.

Fact:

Alzheimer’s disease certainly does not indicate possession by evil spirits nor is it penance for sins committed in previous lives. It is a well-defined medical illness. Treatment should be received from a qualified medical practitioner and not from faith healers or sorcerers.

Myth:

He has no memory problem, he can remember all about his childhood.

Fact:

In Alzheimer’s disease, memory for old events is preserved till the advanced stages of the disease. In the early stages, the ability to learn new things is impaired. Since the

Some famous people who have had Alzheimer’s disease

Adcock, Joe

baseball player

Albertson, Mabel

actress

Andrews, Dana

actor

Balanchine, George

dancer, choreographer

Bing, Rudolph

opera impresario

Brooks, James

artist

Burrows, Abe

author

Chen, Joyce

chef

Copeland, Aaron

composer

DeKooning, Willem

artist

Dorsey, Thomas, A

father of gospel music

Fears, Tom

hall of fame professional football player and coach

Feraud, Louis

prominent fashion designer

Francis, Arlene

actress

Frankovich, Mike

movie producer

French, John Douglas

physician

Goldwater, Barry

Arizona Senator

Hayworth, Rita

actress

Henriquez, Raul Silva

Roman Catholic cardinal, human rights advocate

Klutznick, Philip

real estate developer, adviser to five U.S. Presidents

Some famous people...

Leroy, Mervyn

director - 1987

Lord, Jack

actor

MacDonald, Ross

author

Meredith, Burgess

actor

Murdoch, Iris

author

O'Brien, Edmond

actor

O'Connell, Arthur

actor

Owen, Marv

baseball player

Picon, Molly

actress

Preminger, Otto

director

Quackenbush, Bill

hall of fame professional
hockey player

Reagan, Ronald

former President of USA

Ritz, Harry

performer

Robinson, Sugar Ray

boxer

Rockwell, Norman

artist

Scott, Simon

actor

Shulman, Irving

screenwriter

Schwartz, Betty

first woman to win an
Olympic gold medal in track
events

Swift, Kay

composer

Van Vogt, Alfred

science fiction writer

White, E.B.

author

Wilson, Harold

British Prime Minister

*(List provided by Alzheimer's
Disease International, UK)*

common man assumes that memory for old events is more important, some patients are not brought to the doctor in the early stages of the disease.

Even if a patient with changes in intellectual capability is taken to a doctor, general physicians with limited experience in treating Alzheimer's disease will rarely make a specific diagnosis of this disease. Although awareness is increasing, many misconceptions prevail among medical practitioners.

Doctor:

How can I make a diagnosis if the patient cannot tell me what is wrong with him?



Dhruv Suri

Explanation:

Although the patient cannot give a detailed history, family members certainly can, provided the physician asks appropriate questions of them. Even children cannot give a detailed history, yet paediatricians are able to make accurate diagnoses. A detailed history from family members plays a major role in reaching a diagnosis of impairment in intellectual function, the cause of which could be Alzheimer's disease.

Doctor:

Why make an untreatable diagnosis such as Alzheimer's disease?

Explanation:

Although there is no cure as yet for Alzheimer's disease, a lot can be done to make the patient and the family more comfortable. A physician's role is critical: making an accurate diagnosis, carefully following up the patient for other medical illnesses, treating distressing behaviour and counselling the family, who often suffers more than the patient.

Doctor:

I have many urgent cases waiting for me and Alzheimer's disease cases take up too much of my time.

Explanation:

Management of patients of Alzheimer's disease and support to the family does take time. Not all medicine is based in intensive care units. A doctor has to give sufficient time to patients of Alzheimer's disease in order to reach a diagnosis, prescribe the appropriate treatment and counsel the family. A team approach involving the support of paramedical staff is very useful.

**Letter from President Ronald Reagan to the American people:
Nov. 5, 1994**

My Fellow Americans,

I have recently been told that I am one of the millions of Americans who will be afflicted with Alzheimer's disease.

Upon learning this news, Nancy and I had to decide whether as private citizens we would keep this a private matter or whether we would make this news known in a public way.

In the past, Nancy suffered from breast cancer and I had my cancer surgeries. We found through our open disclosures we were able to raise public awareness. We were happy that as a result, many more people underwent testing.

They were treated in early stages and able to return to normal, healthy lives. So, now we feel it is important to share it with you. In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it will encourage a clearer understanding of the individuals and families who are affected by it. At the moment I feel just fine. I intend to live the remainder of the years God gives me on this earth doing the things I have always done. I will continue to share life's journey with my beloved Nancy and my family. I plan to enjoy the great outdoors and stay in touch with my friends and supporters.

Unfortunately, as Alzheimer's disease progresses, the family often bears a heavy burden. I only wish there was some way I could spare Nancy from this painful experience. When the time comes I am confident that with your help she will face it with faith and courage.

In closing, let me thank you, the American people, for giving me the great honour of allowing me to serve as your President. When the Lord calls me home, whenever that may be, I will leave with the greatest love for this country of ours and eternal optimism for its future.

I now begin the journey that will lead me into the sunset of my life. I know that for America there will always be a bright dawn ahead.

Thank you, my friends. May God always bless you.

Sincerely,

Ronald Reagan

(Reproduced with permission from the Office of Ronald Reagan)

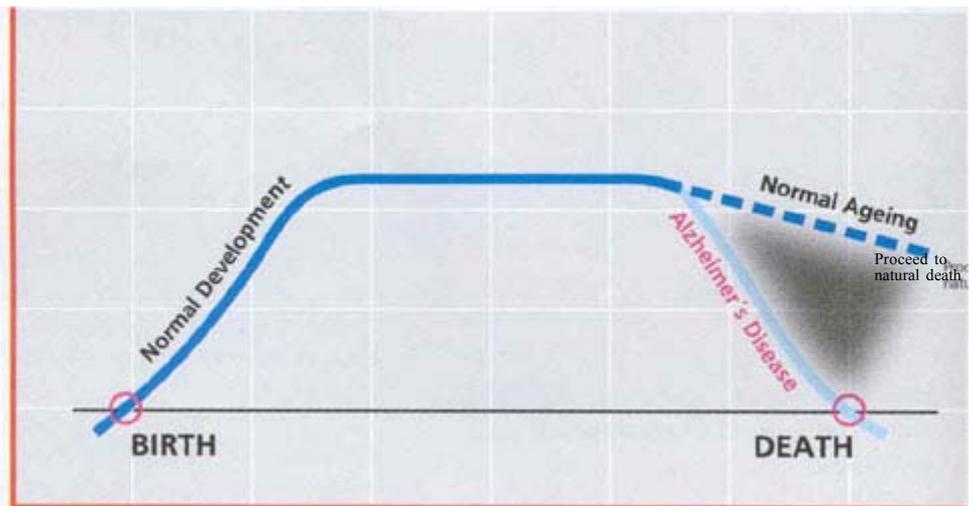
**Mild memory loss:
An inevitable
consequence
of ageing**

**Do not “test” your
memory every day.
This leads to
anxiety. Many
patients who come
to a doctor
complaining of
“loss of memory”
actually have
anxiety or
depression**

The growth cycle is well known to all of us: when a baby is born, it is completely dependent on the mother; next, the child learns to recognize family members and express its needs, then goes to school and university and, finally, grows up to be a healthy adult. Health remains stable for many years, till the onset of decline in bodily functions.

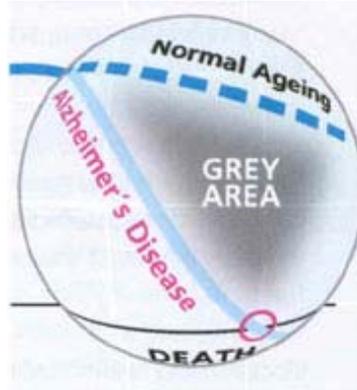
The ageing process occurs in every living species, so also in human beings: greying of hair, wrinkling of the skin, hardening of arteries, aches and pains in joints, weakening of eyesight. The aged often complain that their memory power has decreased over the past few years. While they recall events of the past, they tend to forget more recent events. Remembering names and finding the “right word” seem to be a problem but, as they have discovered, the words do come back later when they stop trying too hard. It is well known that learning gets harder as one grows older. These are the features of advancing years, which are to be expected, but are of no consequence, as they do not interfere with daily life. This basically implies that minor forgetfulness, such as forgetting where one has kept the keys, is of no consequence. Sometimes people get very concerned about minor forgetfulness which is completely normal in old age, and confuse it with Alzheimer’s disease.

This growth cycle of development from birth to teenage to adulthood and the gradual decline with age is depicted in the following graph:



In some people, increasing age is accompanied by a loss of intellectual capability so marked that it becomes a disease. This very rapid decline is shown in the above graph as Alzheimer's disease.

Between the inevitable consequences of ageing and Alzheimer's disease is the "grey area" (shaded grey in the diagram) in which some people suffer loss of intellectual functions that is more than mild and yet not severe enough to be considered Alzheimer's disease. Scientists are unsure of the terminology vis-à-vis these patients. Many terms are in use, for example, minimal cognitive impairment or benign senescence of old age. This is an area of intense research to determine whether these cases will eventually progress to Alzheimer's disease and, if so, who will progress and why, or which of these cases remain in the "grey area".



Proceed to natural death

What is dementia? What is Alzheimer's disease?

Components of intellectual capability

- Memory and learning
- Attention, concentration and orientation
- Thinking (e.g. problem solving, abstraction)
- Calculation
- Language (e.g. comprehension, word finding)
- Geographic orientation

Dementia is a loss of multiple components of intellectual function

Contrary to popular belief, loss of memory is not the only deficit in dementia. However, since it is the most important component in day-to-day living, it causes significant impairment to patients, thus bringing them to a doctor.

What is dementia?

Dr Philippe Pinel (1745-1826), the founder of modern psychiatry, first used the word 'dementia' in 1797. The concept of dementia and the word itself are clearly not new. Dementia is generally defined as the "loss of intellectual abilities (medically called cognitive function) of sufficient severity to interfere with social or occupational functioning" (Diagnostic and Statistical Manual of the American Psychiatric Association).

Intellectual capability is a complex function consisting of many individual 'components', such as memory, problem-solving, calculation, speech, ability to find the way, analyse problems, etc.

Neuropsychologists have developed tests for each of these components of intellectual function. Dementia leads to a deterioration in all these components of intellectual function.

Doctors now know that dementia can occur as a result of many diseases. In some cases, it is not known exactly why the patient has dementia, as in dementia due to Alzheimer's disease. In other cases, there is a contributory cause. These contributory diseases may be located primarily outside the brain, as in certain thyroid diseases or may be due to abnormalities of the brain such as multiple strokes, increased pressure in the brain and degenerative disorders, wherein brain cells are damaged and die. When dementia is the result of certain known causes, it is called secondary dementia.

What is Alzheimer's disease?

The Diagnostic and Statistical Manual of the American Psychiatric Association, which is the reference source worldwide, was first published in 1952 and used the term "Organic Brain Syndrome" to indicate mental abnormalities that were associated with chronic brain disorders. In 1968, the second edition of the Diagnostic and Statistical Manual introduced the expressions 'pre-senile' dementia and 'senile' dementia which was unfortunate, insofar as it implied that cases with onset of disease before 60 years of age (pre-senile) had one disease called Alzheimer's disease, whereas

cases with onset after 60 years of age (senile) had another disease called “senile dementia”. It is now well accepted that, regardless of the age of onset, pre-senile and senile dementias are manifestation of one disease, i.e. Alzheimer’s disease. Alzheimer’s disease has also been called primary degenerative dementia. It is referred to as ‘degenerative’ because the brain cells wither away and die. This disrupts the production and distribution of certain chemicals called neurotransmitters that carry messages within the brain. Brain cells are not damaged from outside by conditions such as severe brain injury, tumours or strokes which affect the brain. As there is no cause for the disease, it is referred to as a ‘primary’ disorder, which in medical terms implies “without cause”.

In patients of Alzheimer’s disease, loss of intellectual capability progresses to such an extent that they cannot remember where they have kept their valuables, money or jewellery and have to search for hours to locate them; or cannot recall the names of their own children or grandchildren. They tend to lose interest or neglect their work, do not keep appointments, have difficulty finding words, or repeat the same questions that have been correctly answered. Occasionally, they forget having eaten and repeatedly ask for meals or lose their way when outside the house. Sometimes, there may be changes in their behaviour or personality.



Alois Alzheimer

Alzheimer’s disease is the most common cause of dementia, accounting for probably 50-70 per cent of all dementias worldwide, as proven by research studies in developed countries and ongoing investigations in

Dementia is a sign of brain disease. It can be caused by many conditions affecting the brain

There are about 100 known causes of dementia. Some common causes are:

- 1 Alzheimer’s disease**
- 1 multiple strokes**
- 1 infections of the brain**
- 1 severe thyroid deficiency**
- 1 severe brain injury**

In 1906, Dr Alois Alzheimer, a famous German pathologist, described a patient who had died of an unusual mental illness.

A woman, 56 years old, showed unreasonable jealousy towards her husband as the first noticeable sign of the disease. Soon a rapidly increasing loss of memory could be noticed. She could not find her way around in her own apartment. She carried objects back and forth and hid them. At times she would begin shrieking loudly.

Her ability to remember was severely disturbed. If one pointed to objects, she named most of them correctly, but immediately afterwards she would forget everything again. When reading, she went from one line to another, reading the letters or reading with senseless emphasis. When writing, she repeated individual syllables several times, left out others, and quickly became stranded. When talking, she frequently used perplexing phrases and some paraphrastic expressions (milk-pourer instead of cup). Sometimes, one noticed her getting stuck. Some questions she obviously did not comprehend. She seemed no longer to understand the use of some objects.

The generalized dementia progressed however. Towards the end, the patient was completely stuporous; she lay in bed with her legs drawn up under her, and in spite of all precautions she acquired bedsores. After 4-1/2 years of suffering, death occurred. Since Dr Alzheimer first described these characteristic abnormal brain changes, the disease is now known as Alzheimer's disease.

developing countries.

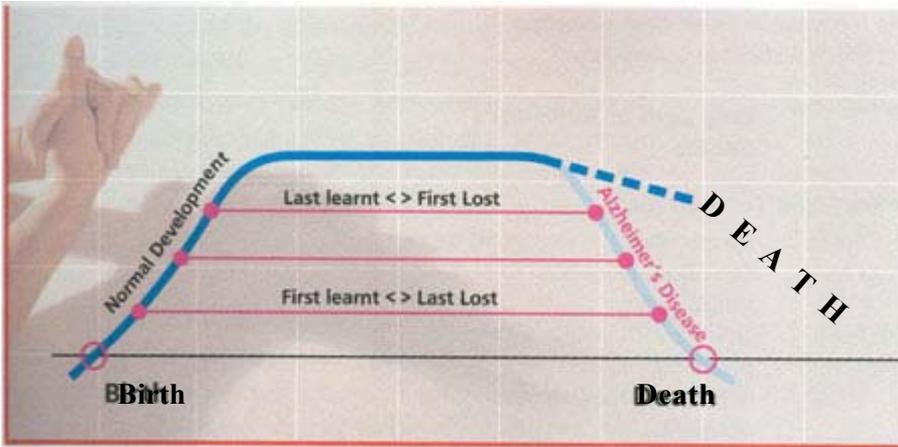
Manifestations of Alzheimer's disease

Patients of Alzheimer's disease generally have three kinds of symptoms. These have been grouped as the A, B, C of Alzheimer's disease.

'A' stands for impairment in Activities of daily living. The ability to perform activities such as brushing, bathing, toilet habits and dressing is lost, usually in the more advanced stages of the disease.

'B' stands for abnormal Behaviour in the patient. This can be very distressing, for example, patients may suspect their spouse of 50 years to be a thief, not recognize their own children, or make sexual advances towards servants. Some patients even become abusive, possibly in contradiction to their past behaviour. Restlessness at night is another pattern which is very troublesome to the entire family.

'C' stands for loss of Cognitive functions. The intellectual capability of the patient is lost. The ability to perform activities that they were very good at, such as arithmetic calculations, planning, giving their opinion and making difficult decisions, is lost. They seem to get confused when confronted with the slightest problem. The most striking aspect is the pattern of loss of intellectual function that follows the principle of "last learnt, first lost". This is shown in the graph across.



In the early stages of the disease, the most complicated functions, such as those learnt in professional college, are the first to be lost. However, basic capabilities, such as toilet habits and recognition of immediate family members, are preserved. As the disease progresses, additional functions are lost. In the more advanced stages, the patient becomes almost child-like, being completely dependent on others in terms of being fed, bathed, dressed and exercised. The rapid progression of this disease leads to premature death, often due to causes such as food going into the lungs or fracture due to a fall. Patients can, however, survive up to 15-20 years after the onset of illness.

The early symptoms of Alzheimer's disease such as forgetfulness, inability to learn new things, loss of concentration, unexplained weight loss and difficulties in walking may be overlooked because they resemble signs of natural ageing. Memory for events in the remote past is preserved in the early stages of the disease.

In healthy individuals, similar symptoms can result from fatigue, grief or depression, many illnesses, vision or hearing loss, the use of alcohol or certain medications, or simply the burden of too many details to remember at once. But when memory loss worsens, family and friends can perceive the existence of more serious problems.

Often there are accompanying problems, such as hearing loss and a decline in reading ability, as well as general physical debility in patients of Alzheimer's disease. These further add to their disability.

Remote memory is preserved in the early stages of the disease

Do not conclude by their ability to remember events in the distant past that he/she has no memory problem. This capability is preserved till late in the progression of Alzheimer's disease.

What is the cause of these symptoms?

A number of disorders may be causing these symptoms and must be ruled out before a diagnosis of Alzheimer's disease can be made. About 20 per cent of suspected Alzheimer's cases turn out to be suffering from some other disorder, half of which are potentially treatable or controllable.

Differences between normal signs of ageing and early Alzheimer's disease

Normal

Early signs of Alzheimer's disease

Memory and Concentration

Periodic minor memory lapses or forgetfulness of part of an experience.
Occasional lapses in attention or lapses in attention or concentration

Displacement of important items.
Confusion about how to perform simple tasks.
Trouble with simple arithmetic problems.
Difficulty in making routine decisions.
Confusion about month or season

Mood and Behaviour

Temporary sadness or anxiety based on appropriate and specific cause.
Changing interests.
Increasingly cautious behaviour.

Unpredictable mood changes.
Increasing loss of outside interests.
Depression, anger, or confusion in response to change.
Denial of symptoms.

Differences between normal and late Alzheimer's disease

Normal

Later signs of Alzheimer's disease

Language and Speech

Unimpaired language skills.

Difficulty in completing sentences or finding the right words.
Reduced and/or irrelevant conversation.

Movement/Coordination

Increasing caution in movement
Slower reaction time.

Visibly impaired movement or coordination, including slowing of movements, halting gait, and reduced sense of balance

Source: Alzheimer's Disease: Early Warning Signs and Diagnostic Resources. Used with the permission of The Junior League of NYC, Inc. 1988
1999 Nidus Information Services, Inc. Well-Connected Report: Alzheimer's Disease. March 1999 (online) www.well-connected.com

Assessment of a patient with Alzheimer's disease, usually involves a team of doctors consisting of a neurologist, psychiatrist and neuro-psychologist, assisted by a radiologist and a pathologist. Assessment involves a series of steps and can take several days to complete. There is no single test which confirms or excludes Alzheimer's disease.

Step 1: In evaluating a patient, the physician will need to check if there is a substantial deterioration in the intellectual function of the aged person relative to his/her previous status, who otherwise seems to be in good physical condition. In medical terms, it is necessary to seek evidence of 'dementia'.

Doctors will administer neuropsychological tests to check various components of intellectual function. Examples of such tests are the Fuld Object Memory Test in which patients are shown 10 objects and then asked to memorize this list of objects and repeat it to the examiner. An average healthy adult should be easily able to recall 7-8 objects. However, patients of Alzheimer's disease can recall only one or two objects. Another neuropsychological test is the Boston Naming Test in which subjects are shown various objects and asked to name them. Most healthy people can easily name these objects, while patients with Alzheimer's disease have trouble naming even such simple objects as a comb or a pen. Similarly, there are neuropsychological tests for speech, calculation, problem-solving and judgement. Based on the results of these tests, loss of intellectual functions can be documented.

Step 2: The doctor needs to ensure that the loss of intellectual functioning is severe enough to disable the person in activities of daily living. Patients of Alzheimer's disease are extremely disabled in function. When loss of intellectual function is so severe that it leads to disabilities, conditions for Step 2 in the diagnosis of Alzheimer's disease are met.

Step 3: In the diagnosis of Alzheimer's disease, it is important to exclude other causes of loss of intellectual function. For this purpose, doctors will take a detailed history of the patient's illness from their relatives, then conduct a comprehensive medical, neurological and

Diagnosis of Alzheimer's disease

Steps in the diagnosis of Alzheimer's disease

There are three steps in the diagnosis of Alzheimer's disease:

Step 1:

Documentation of loss of intellectual function.

Step 2:

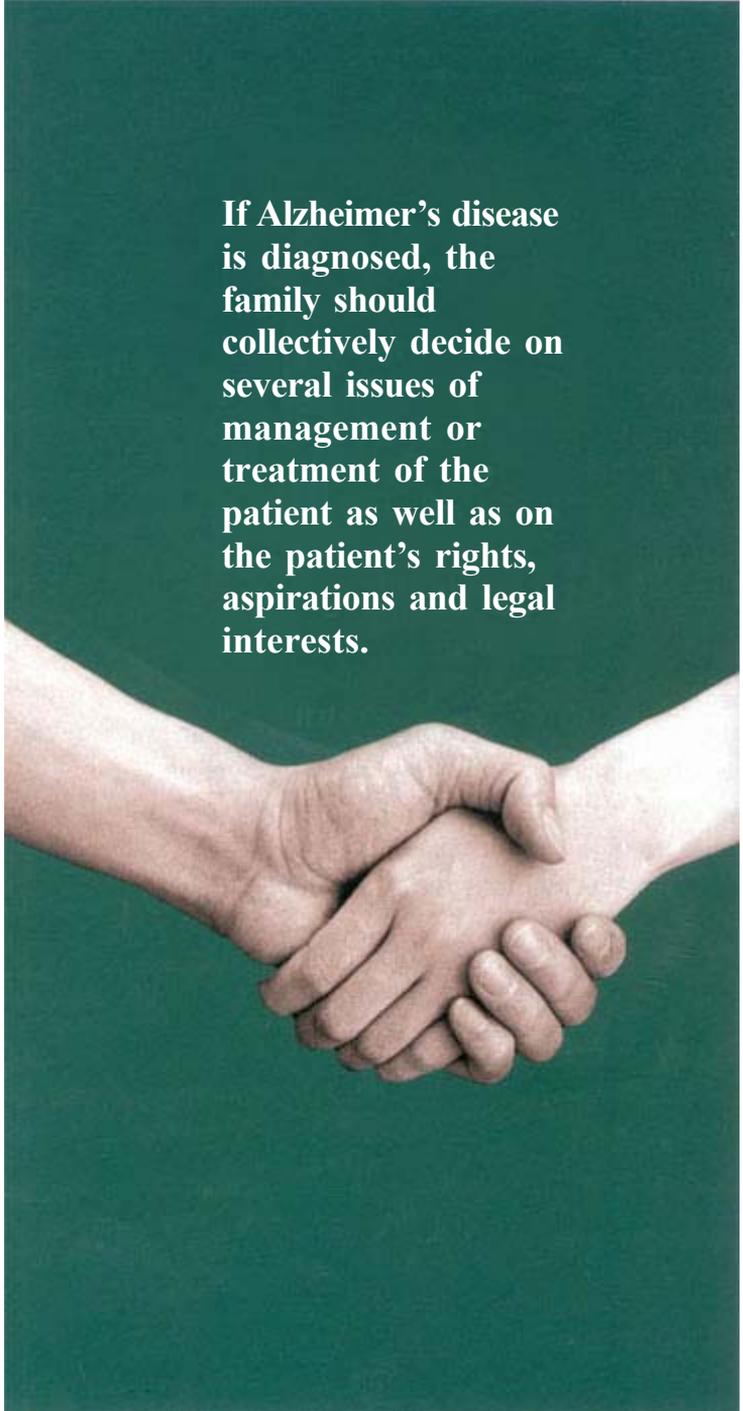
Documentation that the loss of intellectual function is disabling the patient in daily activities.

Step 3:

Exclusion of other causes of loss of intellectual function.

neuropsychological examination. Blood tests and X-ray tests, such as CT scan and MRI scan, will help to exclude conditions such as thyroid disease, brain tumour or stroke. In Alzheimer's disease, CT and MRI scans show a shrinking of the brain. This is medically referred to as "cortical atrophy".

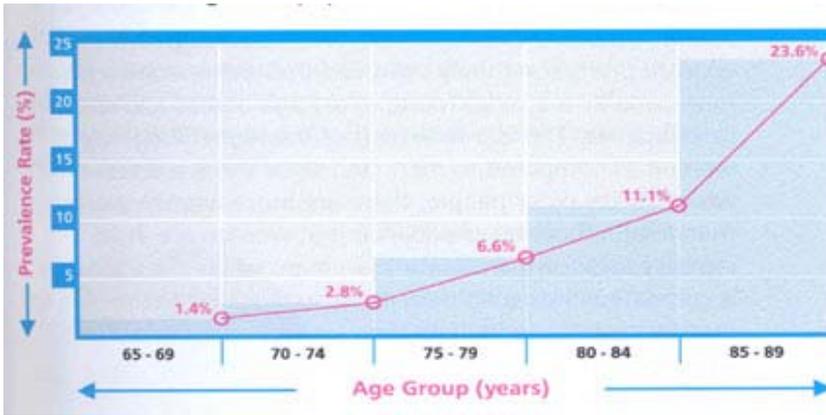
If Alzheimer's disease is diagnosed, the family should collectively decide on several issues of management or treatment of the patient as well as on the patient's rights, aspirations and legal interests.



It is estimated that there are currently about 18 million people worldwide with Alzheimer's disease. This figure is projected to nearly double by 2025 to 34 million. Much of this increase will be in the developing countries, and will be due to the ageing population. Currently, more than 50% of people with Alzheimer's disease live in developing countries and by 2025, this will be over 70%.

Effect of age on risk of Alzheimer's disease

Alzheimer's disease can occur at any age, even as young as 40 years, but its occurrence is much more common as the years go by. In fact, the rate of occurrence of the disease increases exponentially with age, which means that it occurs very rarely among those 40-50 years old, increases between 60 and 65 years, and is very common over 80 years. In November 2000, the National Institute on Aging (USA) estimated that up to 50% of Americans aged 85 years or more may have Alzheimer's disease. Combining the results of several studies, the following rates of occurrence of Alzheimer's disease are estimated in the general population in the West:



Source:
Alzheimer's Disease
International
Factsheet 3,
April 1999

Since the risk of getting the disease increases with age, the number of patients with the illness to be found in any community will depend on the proportion of older people in the group. Traditionally, the developed countries had large proportions of elderly people, and so they had very many cases of Alzheimer's disease in the community at one time. However, the developing countries are now undergoing a demographic transition so that more and more persons are surviving to an old age. For example in India, the 1991 census revealed that 70 million people were over 60 years. This number increased in 2001 to about 77 million, or 7.6%

Some facts and figures

**Why did my father get Alzheimer's disease?
He was such a good man.**

of the population. Similar demographic changes are occurring in other Member Countries of the SEA Region.

In Sri Lanka, the life expectancy is 74.1 (with 9.6% of the population being over 60 years), which is the highest in the Region, followed by Thailand (life expectancy 70, with 8.7% of the population over 60 years). With this increased number of elderly people, there will be many cases of Alzheimer's disease. Thus, the time has come to discuss issues related to Alzheimer's disease in the Member Countries of the Region.

Urban/rural differences

Recent research in India and Africa suggests that the risk of Alzheimer's disease was possibly higher for urban as compared to rural areas. This has raised several important issues for research: What is the deciding factor? Is it increased life expectancy? Is it lifestyle? Is it diet?

Gender differences

It is generally believed that men and women are equally at risk of Alzheimer's disease. However, in developed countries, it is commonly observed that more women than men patients are to be found in old age homes and special care facilities. This is a reflection of the higher longevity of women as compared to men, and since this is a disease which strikes older people, there are more women patients than men. There is no evidence that women are at an increased risk of the disease than men, when the age factor is correlated in existing data. Also, women are better able to care for male patients than men are able to care for female patients. Thus, a woman with Alzheimer's disease has a higher chance of being put into an institution because of her husband's inability to take care of her. However, a man with Alzheimer's disease has a higher chance of his wife taking care of him at home. Thus, a greater number of women patients are found in institutions.

Education

Some research studies have suggested that those with higher education are at a lower risk for Alzheimer's disease than those with less education. Although this has been repeatedly demonstrated in several projects, the reason for this association is unknown.

East-West differences

Studies done in South India, Mumbai and the northern state of Haryana in India have reported very low rates of occurrence of Alzheimer's disease in those at 65 years of age or older, ranging from about 1% in rural north-India (the lowest reported from anywhere in the world where Alzheimer's disease has been studied systematically) to 2.7 in urban Chennai.

Studies from China and Taiwan have also shown a lower risk of Alzheimer's disease as compared to western countries. The low rates of occurrence of Alzheimer's disease in the eastern countries is in striking contrast to data from the western countries.

Community-based studies are of particular interest when they look at populations similar in origin but subject to relocation. Some Japanese reports are important in this respect. Two recent investigations in the rural areas of Japan revealed that Alzheimer's disease occurred in about 3.5% of individuals aged 65 or more. Reported research in 1996 among older Japanese Americans living in Washington and in Hawaii revealed that the number of Alzheimer's disease cases was much higher than that estimated in Japan and closely resembled the findings for North America and Europe.



Similarly, research studies comparing the Yorba's living in Ibadan, Nigeria, and African-Americans living in Indianapolis, USA, are also of interest as the groups share an ethnic background but live in widely different environments. In the Ibadan group, the proportion of Alzheimer's disease cases

was a low 1.4% (similar to rates in India), while the rate for Alzheimer's disease among the African-Americans was estimated at 6.2%.

From the available evidence, it would appear that the number of cases of Alzheimer's disease in Asia, and

particularly in India and Africa, is lower than that reported from studies in developed countries. This raises a major question - why?

There are several possible reasons. Perhaps physicians do not diagnose Alzheimer's disease but use non-specific terms such as senility. Other postulates refer to the socioeconomic realities and the lack of awareness of Alzheimer's disease in the populations studied. It is likely that there is a low survival rate after the onset of the disease. Poor access to technologically-advanced health care may especially hasten the demise of patients, resulting in lower estimates of number of cases. Some have also speculated that the traditional attitude towards the elderly being one of respect, "family members will not force medical care or even food on an older relative who takes to his bed and refuses to eat" - a contributory factor in low survival.

It is possible that there is a lower occurrence of underlying risk factors (or the concomitant presence of protective factors) in the populations surveyed. For example, there is some evidence that the occurrence of a specific gene, Apolipoprotein E ϵ 4, which is a known risk factor in Alzheimer's disease, is lower in the Indian population than elsewhere. This theory seems to be corroborated by the preliminary results from a genetic study of patients and comparable subjects without Alzheimer's disease, which indicated a lower occurrence of Apolipoprotein E ϵ 4 gene in North India compared to the west. Additionally, gene-environment interactions have also been postulated as responsible factors for the lower number of cases in eastern countries.

Risk factors for Alzheimer's disease

Millions of dollars have been spent worldwide in trying to determine why certain people get Alzheimer's disease. However, only two established risk factors, i.e., factors that increase a person's risk of getting Alzheimer's disease have been discovered.

The first identified risk factor is increasing age. As already discussed, the risk of getting Alzheimer's disease increases exponentially with age. But this does not mean that

everyone living to a certain age or beyond will get Alzheimer's disease.

The other identified risk factor is a genetic predisposition.

Since Alzheimer's disease is common among older people, even if many members in a family are affected by Alzheimer's disease, it does not necessarily mean that the disease is being transmitted within the family on a purely genetic basis.

To date, three genetic defects considered as "causative genes" have been identified in patients of Alzheimer's disease. In other words, people inheriting these genes from their parents will get the disease. One defect each is situated on chromosome 14, chromosome 19 and on chromosome 21. There may be other possible genetic defects, as yet unidentified, in patients of Alzheimer's disease. These genetic defects manifest themselves by aggregation of multiple cases of Alzheimer's disease within families affecting multiple generations. However, it must be emphasized that the proportion of all cases of Alzheimer's disease which are inherited on a genetic basis is less than 1-2% of all known cases of Alzheimer's disease.

Another mechanism of genetic effect is the inheritance of a "susceptibility gene". The best known susceptibility gene identified by medical research is the Apolipoprotein E ϵ 4 gene. Inheriting this gene does not mean that the person will get Alzheimer's disease; there are numerous patients who have these genes and do not get Alzheimer's disease, while there are numerous patients who do not have these genes and yet get Alzheimer's disease. Researchers believe that external factors must interact with this susceptibility gene to precipitate Alzheimer's disease. This interaction is referred to as "gene-environment interaction" by medical researchers. The external factors are still unknown. However, since Apolipoprotein E ϵ 4 is known to affect cholesterol metabolism, research in India and Nigeria has suggested that a high-fat diet, as is typical in western countries, may be one of the factors which interacts with Apolipoprotein E ϵ 4 gene to increase the risk of Alzheimer's disease in the West. This is a subject of intense research and remains to be proved.

What are my risks, Doctor?

There is increasing awareness of a genetic predisposition to Alzheimer's disease, i.e., children of patients are afraid that they may inherit the disease. The risk of inheritance on a genetic basis is extremely small.

At the current stage of knowledge, it is impossible to predict who will get Alzheimer's disease. It can strike anyone irrespective of gender, caste, creed, culture or socioeconomic status

Other factors linked to Alzheimer's disease

Increasingly, reports suggest that the use of certain drugs has been associated with reduction of risk of Alzheimer's disease. These include hormones such as the oestrogens in menopausal women, non-steroidal anti-inflammatory drugs, antioxidants such as vitamin E, vitamin B and lipid-lowering agents.

Many other factors have been implicated such as viral infection, aluminium poisoning, as also family history of other genetic defects, and the risk to children born to elderly mothers. However, none of these factors has been proven to increase the risk of Alzheimer's disease.

Cost of Alzheimer's disease

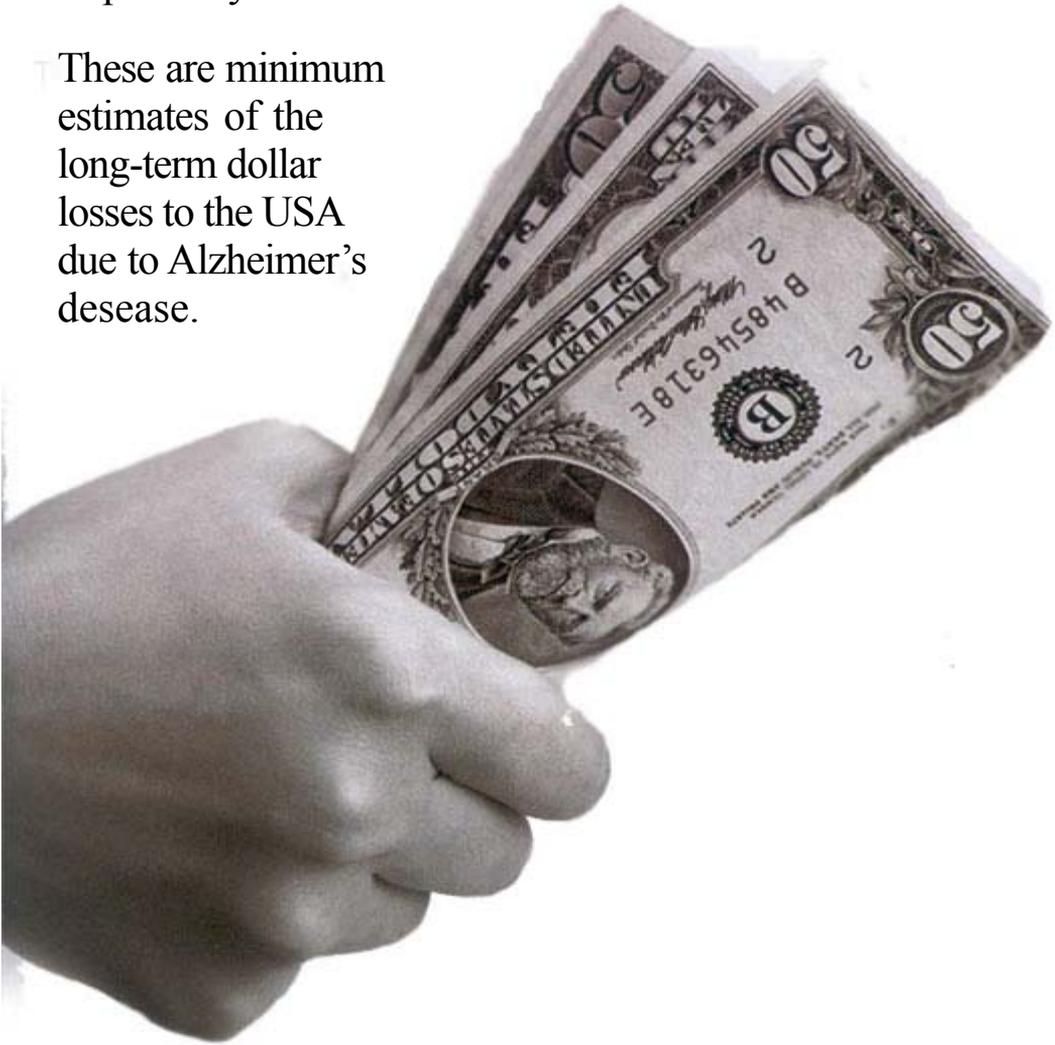
Alzheimer's disease is a chronic and progressive neurodegenerative disorder. It is, therefore, to be expected that the cost of caring for these patients is enormous. Keeping in mind the 1991 levels and future generations of patients of Alzheimer's disease, a researcher in the US estimated that in the year 2000, the direct and total national cost to the US was approximately US\$ 536 billion and US\$ 1.75 trillion respectively. These are minimum estimates of the long-term dollar losses to the US economy at 1991 levels caused by Alzheimer's disease. Similar detailed costing is not available in respect of other countries.

Besides the monetary cost, many spouses, relatives and friends take care of people with Alzheimer's disease. During years of care-giving, families experience emotional, physical, and financial stresses. It is impossible to quantify this suffering.

In 2000, the direct and total national cost to the USA was nearly

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These are minimum estimates of the long-term dollar losses to the USA due to Alzheimer's disease.



**It has been said
about
Alzheimer's
disease that
although the
patient has the
disease, the
family members
suffer the most**

Care-givers and caring

The immediate family members of patients are often elderly themselves and have their own medical problems. The care-givers should never neglect their own health as their well-being is vital for appropriate care of the patient.

In the cultural context of the Member Countries of South-East Asia, care of Alzheimer's disease patients is best provided by lay care-givers. These lay care-givers should be specifically trained in patient care. They must understand what Alzheimer's disease is, and what the patient is capable or incapable of doing. Ideally, continuity of care by the same care-giver is desirable, but this may not be practical. The "fatigue factor" of care-givers also needs to be taken into consideration. Immediate family members should be available to extend psychological support and supervision of lay care-givers. It is not necessary for them to do the physical work themselves.

It has been reported that almost half the patients in a study undertaken in Mumbai, India, were either single or widowed. This finding is significant as research workers came across patients who, having nobody to take care of them, were being looked after by neighbours. Clearly, there is a pressing need for state and community organizations to create the infrastructure necessary for the care of such persons. Ironically, none of the residential institutions for the elderly were willing to take in persons diagnosed with Alzheimer's disease. Since the patients are looked after by their families until the time of death, there is a tremendous need for the education of care-givers and other forms of support. Without this, there is a high risk of patient neglect.

Management of patients of Alzheimer's disease

While there is no specific cure for Alzheimer's disease, there is a need to look after the patients as well as their care-givers. Non-pharmacological interventions and the use of residential and domestic resources, such as day care, respite care and nursing home care, may reduce symptoms and suffering. Another important factor is financial and legal counselling essentially needed to preserve income and take decisions affecting the whole family.

In the early stages of Alzheimer's disease, when intellectual function is reasonably preserved, patients may be encouraged to attend to legal matters and give consent to the types of treatment that they desire. These would form the Advance Directives of the person. An Enduring or Durable Power of Attorney could be prepared in favour of a loved one in the family or some close friend if such procedures are established in the country's legal system. A formal will could also be executed before it is too late as a result of the patient's mental incompetence.

In the later stages of Alzheimer's disease, the patient may not be aware of the consequences of the illness and it would then be a family decision to get him/her assessed and investigated. Treatment would mostly be based on the symptoms observed and arrangements have to be made for the long-term care of the individual by way of providing for care-givers, especially if there are none in the family.

For the patient, the family is the microcosm of the whole world. Accepting that a loved one has Alzheimer's disease, coming to terms with it is the first challenge. The family has to become aware of the condition and how it is likely to progress. This is where several nongovernmental organizations (NGOs) can step in. In many countries, Alzheimer's associations have been set up to offer support and advice to people and families with Alzheimer's disease. They make brochures and pamphlets available to anyone interested in knowing details of the disease, the problems and hazards. Alzheimer's associations are active in India, Sri Lanka and Thailand, but perhaps less so in other countries of the South-East Asia Region. As there are no social security provisions, nursing homes or hospital facilities available in most of them, the basic responsibility for management of the patient rests with the family.

Twelve steps for care-givers

1. Although I cannot control the disease process, I need to remember I can control many aspects of how it affects my relative.
2. I need to take care of myself, so that I can continue doing the things that are most important.
3. I need to simplify my lifestyle so that my time and energy are available for things that are really important at this time.
4. I need to cultivate the gift of allowing others to help me because caring for my relative is too big a job to be done by one person.
5. I need to take one day at a time rather than worry about what may or may not happen in the future.
6. I need to structure my day because a consistent schedule makes life easier for me and my relative.
7. I need to have a sense of humour because laughter helps to put things in a more positive perspective.
8. I need to remember that my relative is not being difficult on purpose; rather that his behaviour and emotions are distorted by the illness.
9. I need to focus on and enjoy what my relative can still do rather than constantly lament over what is gone.
10. I need to increasingly depend upon other relationships for love and support.
11. I need to frequently remind myself that I am doing the best that I can at this very moment.
12. I need to draw upon the Higher Power, which I believe is available to me.

Source: http://my.webmd.com/content/dmk_dmk_article_3961786, 10 Jan 2001

Maintaining a daily routine includes drawing up a fixed timetable for the patient for getting up in the morning, toilet, exercise and meals. This gives the patient a sense of security

Some Suggestions to Care for a Patient of Alzheimer's Disease

Daily routine

As soon as a diagnosis of Alzheimer's disease is made, it is essential to develop a daily routine for the patient to be maintained thereafter. In the early stages of the disease, patients are able to adapt to necessary changes. However, in more advanced stages, only those routines which have been previously established are likely to be maintained and it is almost impossible to make patients adapt to any further changes.

In this context, what may appear to be beneficial for the patient in the family's opinion may in fact be deleterious, such as changing the layout of the patient's room, shifting the patient's bedroom or moving the patient to another house. Such changes create a tremendous amount of confusion and anxiety in the patient's mind.

Maintaining a daily routine includes drawing up a fixed timetable for the patient for getting up in the morning, toilet, exercise and meals. This gives the patient a sense of security.

Patients often deteriorate after dark, a phenomenon known as 'sundowning'. Additional care must be taken during the evening and at night.

Nutrition and body weight

Patients should be provided a well-balanced diet, rich in protein, high in fibre, with adequate amount of calories depending on height and body weight. The total quantity of food can be calculated by a dietician, if necessary. Many patients have "sugar craving" i.e. they love to eat sweet food products. Care should be taken that such patients do not gain weight. The diet should take into account other medical illnesses which require diet modification, such as diabetes or high blood pressure.

The safest diet is a semi-solid one with the consistency of a purée (like *khichri*). Contrary to popular belief, liquids are the most dangerous type of food, as these can be easily aspirated into the lungs. For this reason, soup, which is frequently given to patients, is extremely dangerous.

Personal hygiene

Many patients resist taking a bath. Particular care should be taken about the patient's personal hygiene, including brushing of teeth, bathing, keeping the skin clean and dry, particularly in areas prone to perspiration, such as the armpits and groin. Caustic substances, such as spirit or antiseptic solutions, should not be routinely used on the skin.

Particular care should be taken about the patient's personal hygiene, including brushing of teeth, bathing, keeping the skin clean and dry

Toilet habits and incontinence

Toilet habits should be established as soon as possible and maintained as a rigid routine. This includes conditioned behaviour such as going for bowel movement immediately after a cup of tea. The patient should be taken to urinate at fixed intervals, depending on the season and amount of fluid intake. Prostate trouble, common in elderly men, leads to discomfort, as it causes urgency and frequency of urination, particularly in winters. This should be checked by a doctor.



Incontinence is very distressing to the patient and the family. Once incontinence sets in, the undergarments, pants of the patient and the house in general start reeking of a foul smell. Toilet habits, established in healthy years, must be maintained as long as possible by gently persuading the patient to

go to the toilet and use it. When the first sign of incontinence appear, doctors should check for an underlying cause, if any, such as urinary infection or urinary tract damage.

Constipation is a frequent cause of discomfort to the patient. The quantity of faeces passed each morning should be checked to ensure that the patient is not constipated. Constipation can be avoided by adding fibre supplements and roughage to the diet on a daily basis.

Accidents

Great care should be taken to avoid accidents caused by tripping over furniture, falling down the stairs or slipping in

the bathroom. The reasons for falling include loose and poorly fitting footwear and wrinkled carpets. Ideally, patients should be made to wear soft slip-on shoes with straps which fit securely. Any floor covering must be firmly secured.

Most older people have been driving for years, and in modern cities many people are dependent on their personal cars for transportation. Once early signs of the disease appear, patients should be gently persuaded to stop driving as this can pose a hazard to them and others.

Fluid management

The patients require as much fluid as normal people and this depends on the season. Ideally, sufficient fluid should be given during the day, and only the minimum essential amount of fluid (some water with dinner) after 6 p.m. The last cup of tea should be given around 5 p.m. After that no beverages, including tea, coffee, cocoa or any other caffeine containing drinks, should be given, as all these promote urination. Proper fluid management will reduce bed-wetting and also reduce the number of times the patient will need to get up during the night.

Mood changes are best controlled by keeping a calm environment with a fixed daily routine. The patients should not be questioned repeatedly or given too many choices

Moods and emotions

Some patients of Alzheimer's disease have abrupt changes in their moods and emotions. These changes can be unpredictable. Mood changes are best controlled by keeping a calm environment with a fixed daily routine. The patients should not be questioned repeatedly or given too many choices, such as what they want to eat or what they want to wear. Mood changes are also amenable to distraction, particularly if topics related to the past are discussed or favourite pieces of music played. For example, if music that reminds the patients of their childhood is played, the pleasant associations put them in a nostalgic mood. If mood, behaviour and emotions are distressing to the patient and family, the doctor may prescribe some medications to calm the patient.

Wandering

Patients of Alzheimer's disease often lose their geographic orientation and can get lost even in familiar surroundings. They may be found wandering aimlessly either in the

neighbourhood or far away. It is advisable to have some identification bracelet or card always in their possession. The doors of the house should be securely locked so that the patient cannot leave unnoticed. The patient should always be accompanied while going for walks or for simple chores outside the house.

Disturbed sleep

Sleep disturbances are extremely distressing to the family. Frequently, adult children of patients have to go to work, children need to go to school and the spouse needs sleep at night. If the patient is restless at night or wanders and talks at night, the entire family is disturbed. Sleep patterns must be maintained. Napping during the day should be avoided. Sleeping pills are best avoided as their effect is temporary and frequently unpredictable in patients of Alzheimer's disease. Causes of discomfort at night, such as pain, uncomfortable temperature or prostate trouble, should be checked.

Medical treatment

A knowledgeable and understanding general physician who has the time and willingness to care for patients of Alzheimer's disease should be located. Medical treatment of the disease requires great skill on the part of the physician as the patient is unable to give any history. It is very much like practising paediatrics, where information about the child's illness is obtained from the parents. Similarly, the family can provide information about the patient if appropriate questions are asked of them by the physician. Unfortunately, such skilled general physicians are hard to find in most countries of the Region.

As a principle, patients of Alzheimer's disease need monitoring for coexisting medical disorders such as pneumonia, fractures, stomach upsets and urinary infections. Pneumonia occurs from swallowing food or sputum into the lungs, fractures from falls which can be very minor at times, and stomach and urinary infections from unhygienic conditions. Adverse effects of drugs leading to mental confusion and drowsiness is another issue of concern when patients are confined to bed in the later stages of the illness.

All easily treatable conditions that affect the patient, such as malaria, toothache, trouble in hearing, cataract, diabetes, high blood pressure and heart problems, must be attended to. This will contribute substantially to the patient's well-being. Since patients cannot complain about their symptoms, care-givers need to be alert to signs or symptoms which may suggest illness, such as drowsiness, irritability or refusal to eat.

Vitamins B and E supplements may be helpful in maintaining good health.

What not to give?

Drugs of unproven efficacy, such as brain tonics and brain stimulants, must be discouraged. Often, families and even physicians use these, believing "they can do no harm". However, it should be noted that all medications have some side-effects.

There are many medicines of unproven efficacy sold in the South-East Asia Region. These include medicines from alternative systems, such as Ayurveda, Unani and Homoeopathy, which claim to have drugs effective for abnormalities of loss of intellect in old age. Proof of efficacy of these systems is, however, not available, and more research is needed.



Sedatives, such as the diazepam group of drugs, should be avoided as they induce drowsiness and reduce the already diminished capabilities of the patient.

Many new drugs are being developed and currently undergoing testing. If families wish their patients to participate in these trials, they should consider the decision carefully and then register with a bonafide research centre.

Intellectual capability and behaviour

Unfortunately, no cure for Alzheimer's disease has been found. However, these last few years have seen the appearance of cholinesterase inhibitor drugs which alleviate the clinical features and promote daily activities, at least to some extent. In Alzheimer's disease, one of the deficits is the reduced levels of a chemical in the brain called acetylcholine. The action of this chemical is terminated by

another chemical called acetylcholinesterase. Scientists reasoned that if acetylcholinesterase could be neutralized, more acetylcholine would be available in the brain, thereby reducing the signs and symptoms of Alzheimer's disease. Tacrine hydrochloride was the first of these drugs to be approved, but was not popular due to its adverse effects. Donepezil and rivastigmine soon followed and were found to be effective. All three drugs are unfortunately expensive for most patients in the countries of the Region, but rivastigmine seems to hold the advantage, at least in India, as it is about half the price of the others and is readily available, whereas both tacrine and donepezil are not.

Gingkocor biloba is a plant, an extract from which is being researched for treating patients with mild and moderately severe Alzheimer's disease, but contradictory results have been reported. The basis of its action is not clearly known. Some authorities speak well about the efficacy of selegeline hydrochloride, but additional favourable evidence is needed.

Psychiatric symptoms

These symptoms may co-exist with loss of intellectual function and need appropriate treatment. There is controversy about the use of the antipsychotics haloperidol and thioridazine, probably because of side-effects. Some clinicians, however, find them useful and comparatively cheap. The new atypical anti-psychotics risperidone, olanzapine and clozapine, are useful with less side-effects but very expensive. Trazidone and buspirone are helpful in dealing with agitation. Some experts have also reported that the anti-epilepsy drugs, carbamazepine and sodium valproate, have been found to be useful in controlling abnormal behaviour in Alzheimer's disease, such as sexual behaviour, agitation or sleep disturbances. An informed and competent psychiatrist can effectively deal with many psychiatric symptoms in affected individuals.

Nursing care

Nursing care for patients of Alzheimer's disease is most important, whether at home, in an acute hospital environment, a day-care centre or in a long-term stay institution. Care-givers must be trained to promote the patient's remaining intellectual abilities; help them maintain their independence in attending to their usual functions and

An informed and competent psychiatrist can effectively deal with many psychiatric symptoms in affected individuals

avoid injuries; and provide for a good quality of life. Trained nurses are, however, scarce in most Asian countries. Encouraging results have been obtained in at least two Indian centres, where less qualified nursing attendants are trained in short courses to specifically care for patients of Alzheimer's disease and thus provide help to families looking after afflicted members. Such programmes are cheaper to initiate and ease the burden of harried families.

Psychotherapy

Conventional psychotherapy is not offered to patients of Alzheimer's disease, as it is neither practical nor effective. The forms of psychotherapy most meaningful in reducing symptoms of suffering are group and family therapy, supportive counselling, reminiscence, reality and cognitive therapies. These are options which need to be selected by the multidisciplinary treating teams, based upon specific symptoms and the level of intellectual functioning. The most useful treatment is supportive psychotherapy that provides reassurance and guidance. Behavioural modification and operant techniques are useful in dealing with maladaptive and aggressive behaviours. Enhancing social life, increasing exercise and leading the person into rewarding, enjoyable experiences will enhance the patient's dignity. Filial devotion, respect for elders, love for family and fostering interdependency are accepted and approved values within the cultures of Member Countries of South-East Asia. Even so, we live in troubled times and instances of "elder abuse", abandonment and neglect do occur, though sporadically. There is a need to preserve the human and spiritual values of mutual love, respect, kindness, compassion and understanding. While the younger generations need to realize this, the elderly also have to appreciate the increasing demands on young people. So, care of the elderly, particularly those with Alzheimer's disease, needs to be shared by NGOs as well as governmental agencies.

The most useful treatment is supportive psychotherapy that provides reassurance and guidance

Home care, institutionalization and rehabilitation

Patients afflicted by Alzheimer's disease are, by and large, cared for by their families at home in most countries of the Region. This would appear to be the ideal situation where "TLC" (tender loving care) can be provided and most patients

Efforts need to be made to keep the patient at home in familiar environments

seem to benefit from such an approach. Three years ago, it was stated that even in the USA, of the three million individuals affected by Alzheimer's disease, one million were lodged in nursing homes and two million were cared for at home. Nevertheless, there are occasions when institutional facilities are required for patients whose families are indigent, have emigrated to other parts of the world or have deserted them.

Home care support, day care and respite care are immensely useful programmes in reducing the stress and strain on care-givers. Experience in developed countries suggests that 95 per cent of the care is provided by the family members themselves and among them, the spouse (often elderly, too) and grown-up daughters (already responsible for earning a livelihood and looking after their own children) are the ones who give most of the care. To reduce the 'burden' on the care-givers, the policies of national, social and health services should support a spectrum of health providers, including physiotherapists, occupational therapists, semi-skilled domestic workers, home health aides and nurses. They could assist patients of Alzheimer's disease patient in personal care (bathing, dressing, feeding) or in providing instrumental care (shopping, transportation, household maintenance), manage medical care (injections or medications) and help in occupational therapy.

Families should be involved in educational programmes to enable them to communicate with patients in simple language as soothing, familiar voices and a gentle touch elicit a better response. Additionally, it is necessary to establish a physically safe environment, by installing window bars, door locks and locks on cooking ranges in the kitchen.

Day care

Community centres should be established, wherever possible, to provide daily programmes of structured activities which may include games, crafts, music and recreation. While there may be difficulties in setting up such centres, policy-makers in each country should try to provide the basic minimum facilities. These are cost-effective alternatives to nursing home care which delay

Community centres should be established, wherever possible, to provide daily programmes of structured activities which may include games, crafts, music and recreation

admission to long-stay institutions.

Respite care

Community respite care centres, where patients can be admitted for brief periods, ranging from a few days to a few weeks, can provide some relief to care-givers and possibly re-energize them to continue their prolonged caring functions.

Nursing homes

There is an urgent need to establish at least a few nursing homes in the Member Countries of the Region for patients who are at an advanced stage of Alzheimer's disease. At the same time, delegating care of all patients to special care homes for patients of Alzheimer's disease, as is the practice in the West, may not be the optimum solution for countries in South-East Asia, as the cost is very high and patients are alienated from their own homes and families.



In our Region Alzheimer's disease patients are best cared for at home. Nursing homes may be needed for some, especially in advanced stages of the disease.

The lives of most people are closely bound with the law and old people are no exception. The aged may need to secure help from relatives and friends to attend to business matters or even in simple activities of daily living. This is easy if one has the intellectual ability to do it. Otherwise, someone can be requested or appointed to do whatever is necessary.

Appointment and power of attorney

‘Appointment’ is a legal procedure, whereby an individual can formulate or author a “power of attorney” giving specific instructions to another person who can then exercise the “power of attorney”. Lawyers may be approached for help in this regard. But, what if old people do not know or remember what money or property they have and cannot decide what to do with it?

First, a determination must be made whether the old person is genuinely unaware of the situation due to a severe memory deficit. Second, does the individual know who are the rightful heirs of his/her property or money? Third, is the person capable of deciding on a course of action and understanding the implications? In other words, is the individual ‘competent’?

Competency and decision-making capability

Competence is a legal concept and every person, except children and those unconscious, is presumed to be competent unless determined otherwise in a legal process. The determination of competence is necessary, especially for the aged with impaired mentation, in dealing with issues of medical, legal, economic and social importance.

If the person is judged to be competent, he/she is legally capable of making a will and a “power of attorney” can be rightly exercised through the appointed person. However, the power of attorney is considered invalid if the individual is determined to be incompetent. This is, in a sense, a protective measure for the intellectually impaired person.

While ‘competence’ is a legal concept, the ability to make decisions is based on a medical assessment. This is a determination of “decision-making capacity”. Patients in the

early stages of Alzheimer's disease retain some decision-making capacity, albeit limited.

A seminar held three years ago in India and attended by jurists, doctors and social workers recommended that:

- (1) competence must be determined by a panel of experts which includes a neurologist, a psychiatrist and a psychologist after the performance of at least two examinations at appropriate intervals, the findings of which must be recorded. Thereafter, the degree of competence must be certified by any of the medical experts on the panel;
- (2) the diagnosis of Alzheimer's disease must be accompanied by a determination of the stage of the disorder. This staging must include the doctor's estimate of the individual's decision-making capacity regarding the making of a will, consent to treatment and participation in research.

Last will and testament

The simplest form of a will is: "I, X, gift all my property and belongings to Y". However, most wills are more complex. There may be cases in which the relatives of the mentally incompetent or vulnerable individual, may take unfair advantage of the patient's condition. It may also transpire that the will of a healthy individual is contested later in court on the basis of a state of incompetence when executing the will. In this regard, the following is noteworthy:

- It may be advantageous for an individual and his or her family to arrange for the evaluation of the decision-making capacity of the executor of the will immediately prior to its execution, especially if there is room for doubt, preferably by a team consisting of a neurologist, a psychiatrist and a psychologist. In this context, it must be emphasized that a will is deemed to be valid if the executor is of a sound and disposing mind. He/she must know:
 - the extent of his or her properties;
 - the rightful heirs;
 - knowledge of how the property is to be disposed, and
 - the implications of such a disposition.

The executor of the will must also be able to recall the details of such a procedure for a reasonable period of time. For example, the decision-making capacity would seem dubious if the person concerned could not remember the details from one day or week to another.

- The medical practitioner or practitioners would be well advised to keep detailed records of a person's condition in the event that the will is contested after death, and if a posthumous evaluation of competence becomes necessary. With the currently available advanced technology, some authorities and research workers in India use audio and video-recording techniques as methods of documentation when obtaining informed consent and directives from even illiterate citizens. Such techniques have some merit and are worthy of consideration in appropriate circumstances.

Proxy decision-making

The ethical principles of personal or individual autonomy and informed consent are well recognized internationally.



As an extension of these principles, a person may indicate, when competent, the form of medical management or treatment that he or she would desire at a later stage when incompetent to make decisions. Such wishes expressed by patients are generally respected and effected by the next-of-kin or relatives. At present, such expressed wishes are formalized in North America, Europe and other countries in the form of Advance Directives or Living Wills and exercised through proxy decision-makers who hold a Durable Power of

Attorney or Enduring Power of Attorney which specifies the decisions to be made on behalf of the patient and the nature of such decisions.

When an individual is severely impaired intellectually, it is nevertheless mandatory to respect the patient's wishes expressed at the earlier stage of mental competence. This necessitates obtaining informed consent from the next-of-kin or proxy decision-makers prior to initiating medical or

treatment procedures. The view has been strongly expressed that Advance Directives or Living Wills made by individuals have to be respected, on condition that they (1) do not require the direct termination of life which is contrary to law; and (2), are not legally binding on medical and nursing staff, or health institutions, in the event that the directives are deemed countertherapeutic or objectionable in conscience on professional, ethical or moral grounds.

In this context, the following would help:

- While fully competent, individuals should be enabled to nominate and authorize, in advance, proxy decision-makers who will act on their behalf when their decision-making capacity may be impaired. This authorization must specify the areas (health care, personal affairs, estate) within which proxy decisions can be taken;
- In the absence of such an authorization, proxy decisions can be sought from other members of the individual's family in a hierarchical manner. First, from the spouse, followed by the eldest child, and so on. In the absence of next-of-kin, or when the individual's next-of-kin are themselves deemed to be incompetent, or when the individual does not want decisions to be made by the next-of-kin, an appropriate court may appoint a proxy or proxies to make decisions in the patient's best interest, and
- Provision should be made for the proxy's decisions to be made accountable periodically at intervals to a court having jurisdiction.

Some of these points may require legislative support to clarify or amplify the existing legal framework. Legislative action on the subject becomes necessary in countries like India because the law does not contain any provision for a person to delegate any authority to a proxy decision-maker on his or her behalf in personal matters affecting the body. In substance, the person concerned would be creating an alter ego (another self of himself or herself) to function on his/her behalf. Or, to put it in different words, he or she would be transferring to another person his or her own freedom of granting or refusing consent to an invasion of his or her bodily privacy, integrity or personality. In India, it

was thought that such a vital modification concerned with the capacity to consent cannot be effected without properly drafted legislation and accompanied by appropriate safeguards. Such legislation would expand the role of a “power of attorney”.

Informed consent for treatment and research

It is mandatory for a treating physician to obtain informed consent from a patient before initiating medical investigation or treatment. Informed consent, by definition, requires it to be competent, voluntary, informed and comprehensible. These requirements may not necessarily be fulfilled when an individual is intellectually impaired, and so it would be safe to assume that the person is unable to give such consent. The topic of informed consent has been discussed in India, especially vis-à-vis rural areas, where the cultural traditions are different and illiteracy is rampant. Under these circumstances, there should not be an insistence on the adoption of western methods of obtaining informed written and signed consent; rather suitable



adaptations should be made.

To resolve this, it was recommended at a seminar in India attended by jurists, doctors and social workers, that:

- (1) if a physician has any doubts regarding a patient's ability to give consent, a full assessment of decision-making capacity should be sought. In the event that the patient is declared incapable, the consent of the proxy decision-maker should be sought. In such a situation, the level of decision-making capacity required depends on the type of medical procedures or research proposed. When the risk of disability to the subject of the treatment/procedures is great, it would require a demonstrably higher degree of decision-making ability. This is particularly applicable to those who agree to participate in research activities, and especially in non-therapeutic ones;
- (2) if the evaluation of decision-making capacity indicates that a patient is incapable of making appropriate decisions in a particular context, any consent obtained from such a subject is invalid;
- (3) in the context of research among the possibly intellectually impaired, there must be an assessment of the decision-making capacity of each participating individual;
- (4) all subjects of research as well as their proxy decision-makers must be fully informed about the nature of the research and, in particular, of its therapeutic or non-therapeutic character, the risks involved, as well as the direct benefits or disadvantages, if any;
- (5) patients or their proxy decision-makers invited to participate in research, should be clearly advised that their non-participation in the research activity will not disqualify them from continuing medical or nursing care;
- (6) research workers should be particularly cautious about avoiding the participation of mentally incompetent individuals in hazardous or life-threatening procedures, diagnostic or therapeutic, even if their proxy decision-makers provide consent;

- (7) psychological testing poses the problem of informed consent. Most of the participants were of the opinion that the provision of a response by an individual to the test items presented by a psychologist, implies the existence of assumed consent between the two parties, and
- (8) doctors and research workers in rural areas, and those dealing with the illiterate in India, were encouraged to respect the personal autonomy, cultural traditions and wishes of their subjects by adapting methods of obtaining informed consent through village leaders, heads of families and other respected persons. They were also advised not to insist on obtaining the signatures or thumb impressions of those to be treated or included in research projects but rather to adopt other methods, for example, recording that the relevant information had been provided and understood prior to commencement of treatment or research.

The reader will readily appreciate why it is so imperative to determine in detail the state of mind of the aged. Some vital questions that need to be asked are:

- Is the seemingly intellectually impaired person in fact competent, or incompetent?
- Is the competence retained for certain issues, such as deciding on acceptable medical tests or treatment, but not retained for the purpose of making a will?

In the early stages of Alzheimer's disease, an individual may retain enough mental function to be legally permitted to make a will. It becomes important for the physician or health care team to advise the family and the patient in a sensitive manner to take timely action for drawing up a will before the progression of intellectual impairment to such a degree that it is too late. Likewise, the old may be tactfully informed and their preferences about their options sought regarding the various forms of medical investigations and treatment that they may be subjected to in various situations.

What the patients can do for themselves

At the present state of understanding about the causes of Alzheimer's disease, there is nothing anyone can do to guarantee that he or she or their loved ones will not get Alzheimer's disease. As a consequence, various hypotheses have been advanced with regard to its prevention. The absence of proof does not mean these hypotheses and clinical impressions have to be abandoned. Rather, they have to be borne in mind and accepted or rejected when evidence suggests so. Time will tell fact from fiction.

At the moment, every one should practise the well-known methods of health protection and promotion, such as eating right, exercising and abstaining from tobacco and alcohol. Although not directly linked to the prevention of Alzheimer's disease, good health in youth is a prerequisite to good health in old age.

Good health also requires paying timely attention to all easily treatable conditions which are known to adversely affect health, such as high blood pressure, obesity and diabetes. Control of these factors would be a protective measure against heart attacks and strokes and may also safeguard against Alzheimer's disease, although this remains conjectural.

There is an increasing awareness about the harmful effects of stress and mental tension on the human body. Researchers hope to learn much more in this century about "the mind" since this is believed to mediate emotions and stress. The age-old tradition of meditation is well known to control stress, so its practice is certainly desirable.

What the family can do

Family members should be aware of early warning signs which may suggest that one of the older members may be on the verge of developing Alzheimer's disease. Early diagnosis and early intervention can be beneficial both to the patient and the family.

As the disease progresses, the family remains the main pillar of support for the patient. The traditions of eastern culture and the lack of special care units make it clear that the patient is best cared for within the family. However, this

What can be done?

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imposes an immense burden on the family for which support should be sought. Families and others will benefit by joining self-help groups or support groups, as these are well known to provide social and psychological support to members. If there is no support group in the area, families may wish to start a new group.

What the community can do

Families with a member suffering from Alzheimer's disease carry a huge burden of caring and need the support of neighbours and the community. Neighbours can also provide respite care to the tired care-giver.

Special training programmes for lay care-givers can be organized in the community. In addition, awareness campaigns can be launched by community activists to educate those who may not be aware of this dreadful disease and its early manifestation.

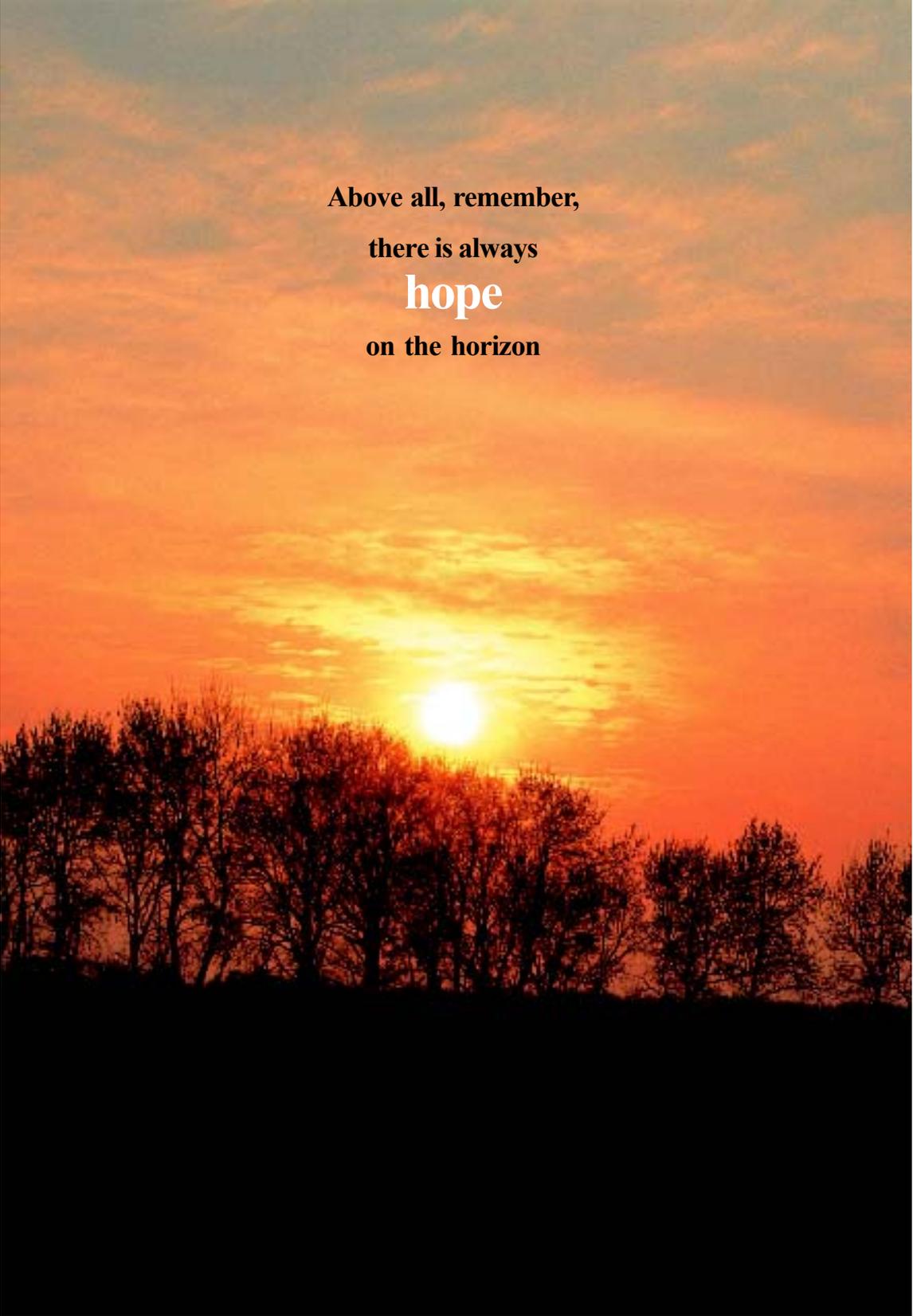
What NGOs can do: Alzheimer's Disease International

Alzheimer's Disease International (ADI) can be reached at their website: <http://www.alz.co.uk> and they can share information and experiences and learn from one another

Alzheimer's Disease International (ADI) is an umbrella organization of 57 national Alzheimer's associations throughout the world, and is in official relationship with the World Health Organization. Each national Alzheimer's association, which supports people with this disease and their families, is an ADI member. ADI's key aim is to build and strengthen Alzheimer's associations worldwide so that they are better able to meet the needs of people with Alzheimer's disease and their care-givers.

Alzheimer's associations around the world provide practical and emotional help and information to families, health care professionals and the community; advocacy efforts to governments; training family and professional care-givers and provide direct services such as day and respite care.

ADI is attempting to reach out to patients and care-givers worldwide by encouraging the formation of new Alzheimer's associations. By coming together, forming partnerships and sharing expertise and knowledge on a global basis, Alzheimer's associations are better able to tackle the challenges of this disease.



**Above all, remember,
there is always
hope
on the horizon**



**World Health
Organization**

Regional Office for
South-East Asia