

AGEING GRACEFULLY

Diversity of Dementia

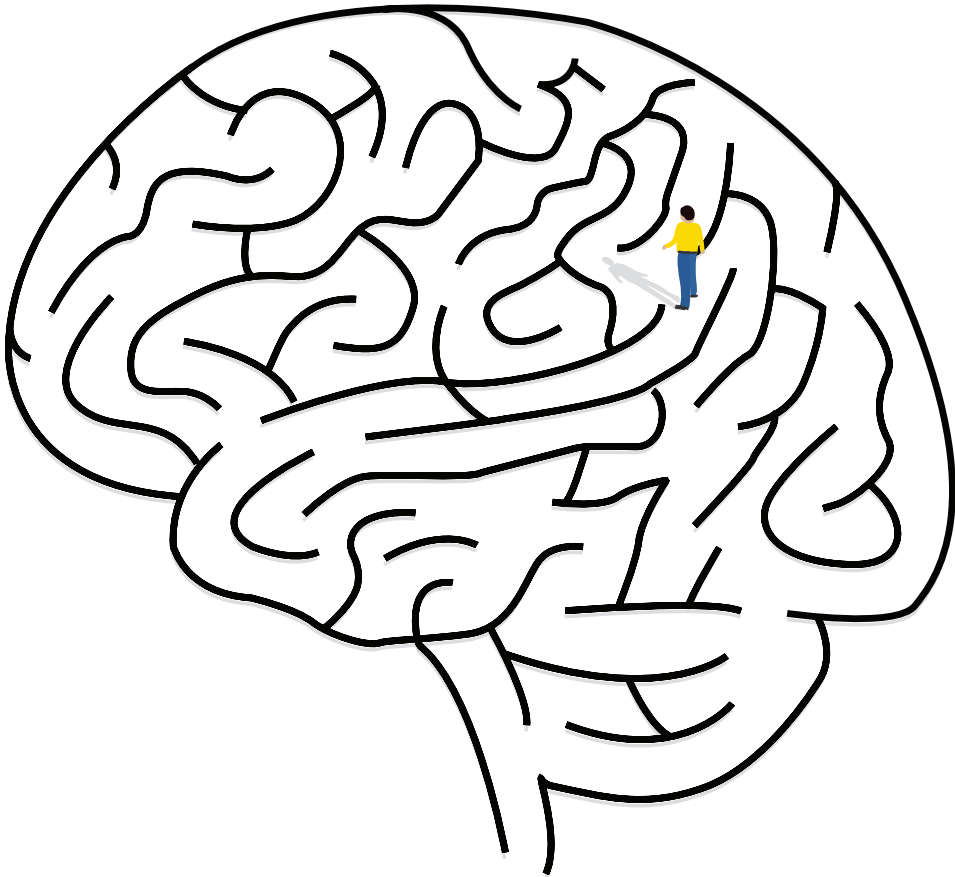


**World Health
Organization**

Regional Office for South-East Asia

AGEING GRACEFULLY

Diversity of Dementia



**World Health
Organization**

Regional Office for South-East Asia



**World Health
Organization**

Regional Office for South-East Asia

Ageing Gracefully: Diversity of Dementia

ISBN 978-92-9022-571-3

© World Health Organization 2017

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this license, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons license. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: "This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition".

Any mediation relating to disputes arising under the license shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization.

Suggested citation. Ageing Gracefully: Diversity of Dementia. [New Delhi]: World Health Organization, Regional Office for South-East Asia; [2017]. Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. CIP data are available at <http://apps.who.int/iris>.

Sales, rights and licensing. To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <http://www.who.int/about/licensing>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement. The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

Printed in India

Compiled by DR VIJAY CHANDRA

Consultant in Neurology and Memory Disorders,
New Delhi, India

For technical information, please contact:

DR NAZNEEN ANWAR, Regional Adviser
Mental Health

DR THAKSAPHON THAMARANGSI,

Director
Department of Noncommunicable Diseases and Environmental Health

Mental Health Unit

Department of Noncommunicable Diseases and Environmental Health
World Health Organization
Regional Office for South-East Asia
New Delhi, India
Email: anwarna@who.int

CONTENTS

Abbreviations	4
Foreword	5
Historical background	8
Inevitable consequences of ageing of the body and brain	10
Facts about dementia and Alzheimer disease	12
What is dementia?	15
Types of dementia	19
Differentiating the types of dementia	25
Risk and protective factors for dementia	28
Caregivers and caring	37
What can be done?	53
Good news	59
References	61

ABBREVIATIONS

AD	Alzheimer disease
CT	Computed tomography
FTD	Frontotemporal dementia
GDO	Global Dementia Observatory
LBD	Lewy body dementia
LMIC	Low- and middle-income countries
MID	Multi-infarct dementia
MRI	Magnetic resonance imaging
NCD	Noncommunicable diseases
NGO	Nongovernmental organizations
SEAR	WHO South-East Asia Region
TLC	Tender loving care
U.S.A.	United States of America
VaD	Vascular dementia
WHO	World Health Organization

FOREWORD



Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain the activities of daily life. As early as 800 BC Ayurvedic physicians from India used the Sanskrit term “smriti bhransh” to describe loss of memory in older people. However, it was only in 1906 that German doctor Alois Alzheimer described a case of memory loss in a medical publication. This condition is now known as Alzheimer disease. The manifestation of this disease is called dementia.

In 2015, dementia affected 47 million people worldwide, and is predicted to increase to 75 million in 2030 and 132 million by 2050. Globally, nearly 9.9 million people develop dementia each year; this figure translates into one new case every three seconds, making dementia an important public health issue to address. Dementia has several implications for the WHO South-East Asia Region, nearly 60% of people with dementia currently live in low- and middle-income countries (LMICs) and the majority (71%) of new cases is also expected to occur in such countries. Evidence shows nearly 90% of people with dementia in LMICs do not receive any diagnosis, treatment or care.

WHO is supporting Member States in developing expertise in the identification, diagnosis and management of persons with dementia. The Region will be working towards mainstreaming dementia into the policies for

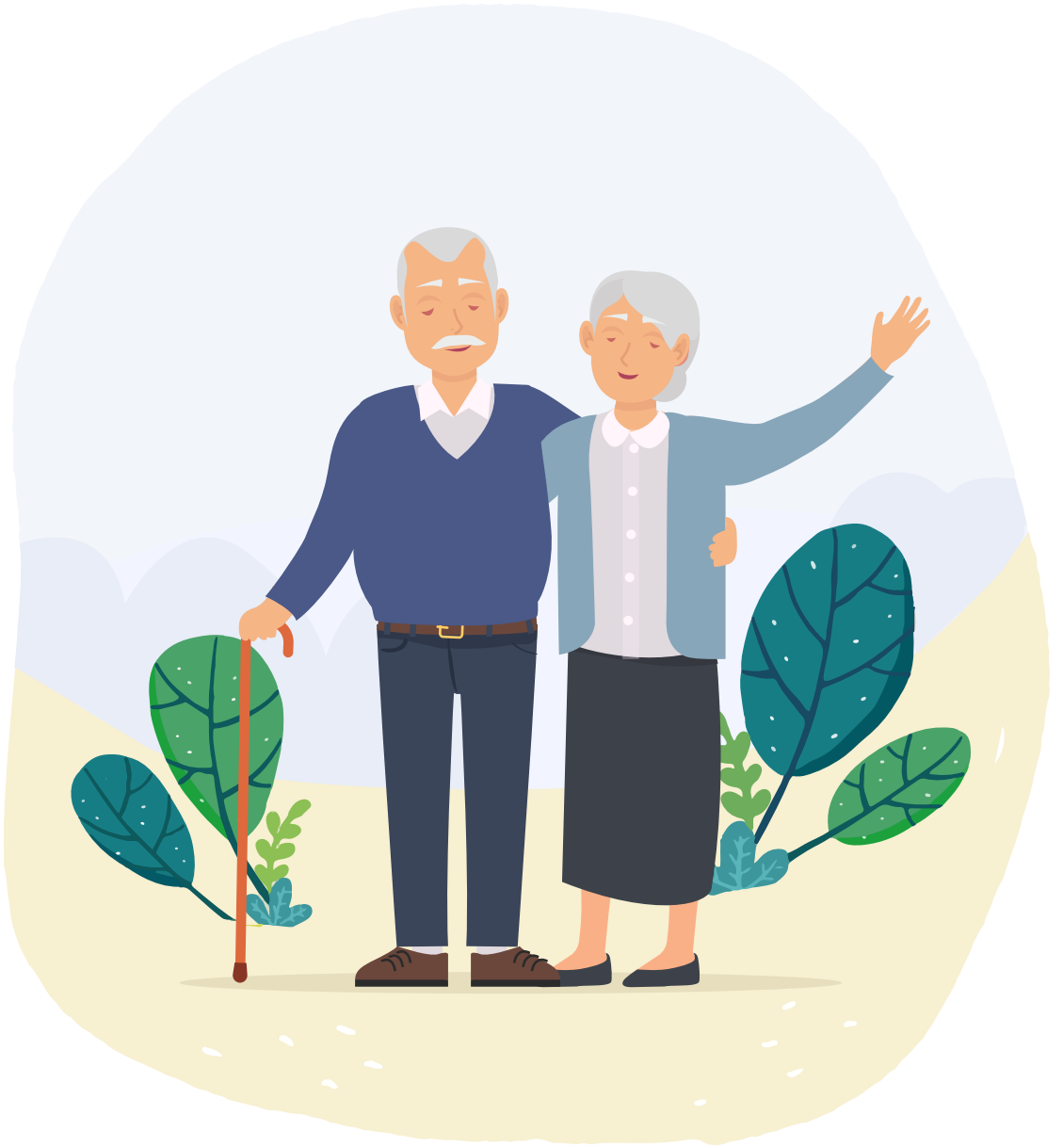
noncommunicable diseases (NCDs), as dementia and NCDs have shared risk factors. The Seventieth World Health Assembly in May 2017 adopted the Global Action Plan on the public health response to dementia.

The WHO Global Dementia Observatory (GDO) is a knowledge translation and exchange platform to support evidence-based service planning and strengthening of policies and social care systems. Three Member States of the WHO South-East Asia Region – Bangladesh, Maldives and Myanmar – are participating in the first phase of this initiative.

This publication on dementia is focused on improving dementia awareness, reducing stigma and accelerating focus on risk reduction by promoting a better understanding of dementia, including respect for human rights of people living with it. I believe this publication will be valuable information for older people, families with dementia patients, and policy-makers. The aim is to increase knowledge to address barriers to dementia care and to have dementia policies, plans and programmes framed within a public health approach.



Dr Poonam Khetrpal Singh
World Health Organization
Regional Director



CHAPTER : 1 HISTORICAL BACKGROUND

The function of a human brain is broadly termed as “intelligence”. In medical terms intelligence is called “cognition”. A decline in cognition when severe is termed as “dementia”.

Dementia is derived from the Latin word, “*de*” = out from + “*mens*” the mind, which translates to loss or impairment of mental powers due to a disease. The word “*démence*” existed in the French language as far back as 1381.

During the period 2000 - 1000 BC the Egyptians and Greeks were aware that advancing years and old age were associated with disorders of 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 during the first and second centuries AD respectively, 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 (loss of control of urine). The concept of dementia in the aged (Alzheimer disease) is widely known in Thailand, as “*roke long*”.

The changes in the mind brought on by old age have also been referred to by William Shakespeare in his plays “As You Like It”, “Macbeth” and “King Lear”, The last one written in 1606, aptly describes what is known even today as dementia.

As per the Diagnostic and Statistical Manual of the American Psychiatric Association, 1994, Dementia is the “loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning”.

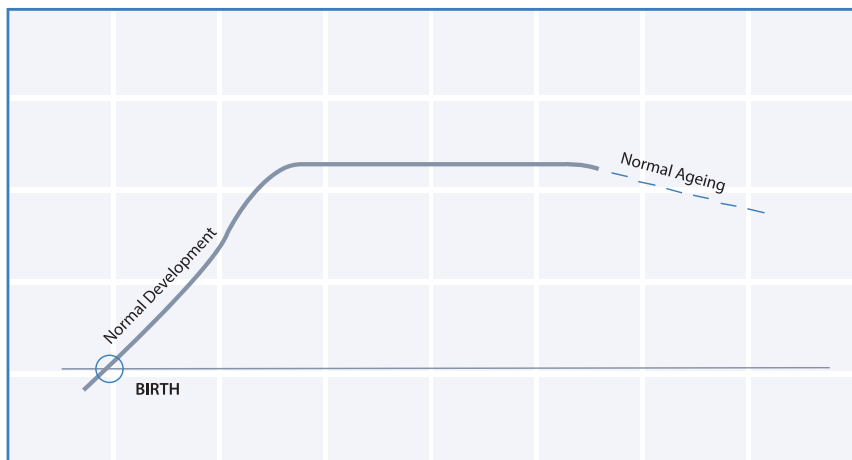
CHAPTER 2: INEVITABLE CONSEQUENCES OF AGEING OF THE BODY AND BRAIN

The growth cycle is well known. 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: graying of hair, wrinkling of skin, hardening of arteries, aches and pains in joints, weakening of eyesight etc. These are some “inevitable” “consequences of ageing. They occur to a variable extent in people, from minor to severe.

Similarly, the brain also ages. Older persons 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 the words do come back later when they stop trying too hard. There is a decline in the ability to form new memories or learn new things. These are features of advancing years, which are to be expected, but are of no consequence, as they do not interfere with daily life. This implies that minor forgetfulness, such as forgetting where one has kept 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 disease.

The growth cycle of development from birth to teenage to adulthood and the gradual decline with age is depicted in the following illustration.



CHAPTER 3: FACTS ABOUT DEMENTIA AND ALZHEIMER DISEASE

Ageing and dementia: a fallacy

Dementia is NOT “normal old age”. Every elderly individual does not get this disease. There are well known examples of people in their 80s who have studied and written books on complex subjects.

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 some communities. 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 family member’s disease.

I forget, could I be getting dementia?

Forgetting small things is a part of growing old. This is called “Inevitable consequence of ageing”. This means that just as every organ in the body changes with age (grey hair, need for reading glasses etc.); so also brain function declines with age. Thus to forget things such as where you have left keys or spectacles is of no consequence but if you cannot recognize your spouse or forget your way around the neighbourhood, this is significant and may suggest dementia.

Alzheimer disease can affect anyone

Former President of USA, Mr Ronald Reagan, had Alzheimer disease. Other famous people who had Alzheimer



disease include Mr Harold Wilson, former Prime Minister of Britain, Mr Sugar Ray Robinson, famous boxer, Ms Betty Schwartz, the first woman to win an Olympic gold medal in track events. Besides these and other famous people, there are millions of common people both rich and poor who have or will get Alzheimer disease.

Abnormal behaviour in a patient is not “madness”

Although some patients with dementia have behavioural symptoms, these are an integral part of the disease process. Under no circumstances should this be considered to be ‘madness’ or being possessed by spirits. The patients are unable to control their behaviour and therefore, appropriate treatment is necessary.

There is no cause for worry as long as behaviour remains a ‘minor’ deviation from 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.

Do not judge intellectual capacity by remote memory

In dementia, memory of 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 common man assumes that memory of 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 dementia will rarely make a specific diagnosis of this disease. Although awareness is increasing, many misconceptions prevail among medical practitioners.

Some physicians hesitate to make a diagnosis of an “untreatable” condition.

Some physicians may consider it “futile” to spend time making a diagnosis of an “untreatable” condition such as dementia or Alzheimer disease. Although there is no cure as yet for Alzheimer 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 suffer more than the patient.

Do not “test” yourself repeatedly for memory loss

With increasing awareness of dementia and Alzheimer disease some people repeatedly keep testing their memory. Even minor memory lapses are interpreted as the onset of dementia. It must be remembered that a common cause of memory lapse is anxiety or depression, so every episode of forgetting a name should not lead to worry.

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.

CHAPTER 4: 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).

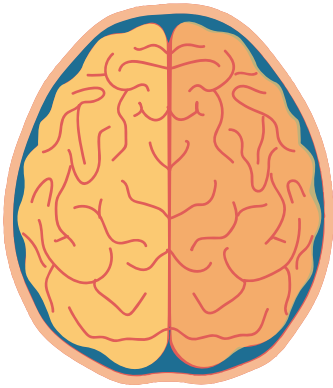
Intellectual capability is a complex function consisting of many individual 'components', such as memory, problem-solving, calculation, speech, ability to find the way, analyse problems, etc.

In patients of dementia, 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.

Differences between Signs of Normal Ageing and Early Dementia

	Normal Ageing	Early Dementia
<i>Memory and Concentration</i>	Periodic minor memory lapses	Misplacement of important items
		Confusion about how to perform simple tasks
	Occasional lapses in attention or concentration	Trouble with simple arithmetic
		Difficulty in making decisions
		Confusion about month or season
<i>Mood and Behaviour</i>	Temporary sadness or anxiety based on appropriate cause	Depression, anger or confusion in response to change
	Changing interests	Increasing loss of outside interests
	Increasingly cautious behaviour	Unpredictable mood changes
		Denial of symptoms



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

Neuropsychologists have developed tests for each of these components of intellectual function. Dementia leads to deterioration in all these components of intellectual function, i.e. 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 families come to doctors complaining of memory problems in their relative.

Doctors now know that dementia can occur as a result of many diseases, i.e. 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:

- Alzheimer disease (AD)
- Lewy body dementia
- Multiple strokes (Vascular dementia, VaD)
- Infections of the brain
- Severe thyroid deficiency
- Severe brain injury

In some cases, it is not known exactly why the patient has dementia, as in dementia due to AD. 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.

CHAPTER 5: TYPES OF DEMENTIA

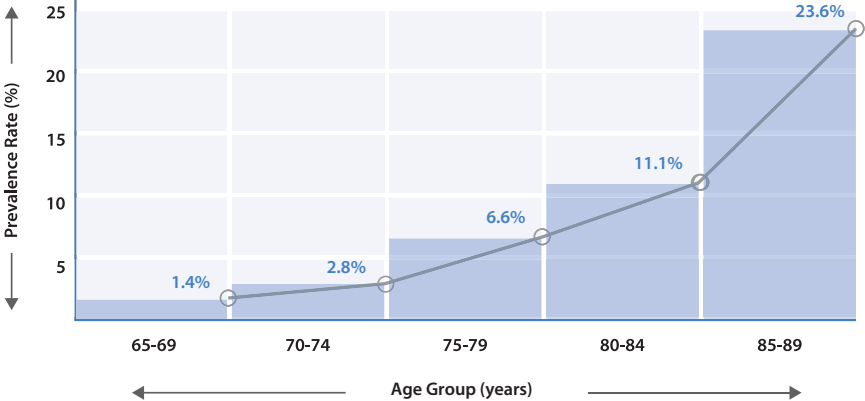


Alzheimer Disease (AD)

In 1968, the second edition of the Diagnostic and Statistical Manual of the American Psychiatric Association introduced the expressions ‘presenile’ 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 AD, 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, presenile and senile dementias are manifestation of one disease, i.e. AD. AD 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, tumors 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”.

AD is the most common cause of degenerative dementia world-wide including in low-and middle-income countries, accounting for about 50% – 75% of all cases of dementia. It has a gradual onset usually after 60 years of age. AD 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 disease. Combining the results of several studies, the following rates of occurrence of AD are estimated in the general population in the West:



Source: Alzheimer's Disease International Fact sheet 3

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, developed countries had large proportions of elderly people, and so they had many cases of AD in the community at one time. However, developing countries are now undergoing a demographic transition so that more and more persons are surviving to 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% of the population. Similar demographic changes are occurring in other Member States 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 AD. Thus, the time has come to discuss issues related to AD and other dementias in Member States of the Region.

AD has a progressive course with longevity of approximately 8-14 years after onset. There are no fluctuations in the condition of the patient except a sudden decline due to a concurrent medical illness from which the patient makes a slow recovery.

Risk and protective factors are discussed in another section.

Vascular Dementia (VaD)

VaD was previously termed as multi-infarct dementia (MID). This is the second most common cause of dementia accounting for about 20% – 30% of all cases of dementia. It is believed that this kind of dementia is more common in communities with a high salt intake resulting in high prevalence of hypertension.

In this condition, the patient suffers multiple strokes which are diagnosed based on clinical examination and CT or MRI scans.

More recently there is evidence that damage to small vessels of the brain can also lead to dementia, thus the term vascular dementia (VaD) is used for all causes of dementia due to vascular damage.

The correctable risk factors for VaD are well known and consist of diabetes, hypertension, high cholesterol and tobacco use. Other risk factors include advancing age, male gender and family history of stroke.

As discussed in another section, control of these risk factors is probably responsible for a decline in the incidence of strokes, VaD and other dementia mostly in developed countries.

Lewy Body Dementia (LBD)

LBD is probably the second most common form of degenerative dementia after AD. It is characterized by deficits in attention, fluctuating cognitive function,



recurrent visual hallucinations and motor features of Parkinsonism with repeated falls. Other features include fainting episodes, autonomic dysfunction, and hypersensitivity to some older generation anti-psychotic medications and sleep disorders.

A recent study from Delhi, India which analysed the first 100 cases seen at a dementia clinic reported that the commonest type of dementia was LBD. This finding should be explored by other researches in the Region.

There are several clinical implications of symptoms of LBD. Hallucinations are sometimes treated with older anti-psychotic medications (haloperidol) and features of Parkinsonism are treated with medicines specific for Parkinson's disease. Both these can have adverse effects. Frequent falls can lead to hip or spine fractures.

The most positive aspects of this condition is that symptoms of dementia are mild and progress more slowly compared to AD. Also in the experience of some clinicians, the condition responds very well (particularly hallucinations) to a medication called memantine.

Frontotemporal Dementia (FTD)

The understanding of the concept of FTD has evolved over the last 10 years. The initial concept of degeneration most marked in the frontal lobe as seen on CT scan was termed as "Pick's disease".

Now FTD has emerged as a part of a clinically, pathologically and genetically heterogeneous group of

disorders in which relatively selective degeneration of the frontal and temporal lobes of the brain as seen on CT or MRI is a prominent and common feature.

These group of disorders, although quite distinct from each other have some common features. They usually affect people under 65 years of age with approximately 30% – 50% of cases reporting a positive family history of dementia. It is the second most common cause of dementia in people under 65 years of age.

FTD can present with diverse clinical presentations: behavioural symptoms, speech problems (including primary progressive aphasia), with motor neuron disease, corticobasal syndrome (significant atrophy of the cortex and midbrain parts of the brain as seen on CT or MRI scan) and progressive supranuclear palsy. Thus there is no one clinical presentation.

Other causes of dementia

Other causes of dementia include severe brain injury, thyroid deficiency, brain infection, or depression (pseudodementia) etc.

CHAPTER 6: DIFFERENTIATING THE TYPES OF DEMENTIA

Assessment of a patient with dementia, usually involves a team of doctors consisting of a neurologist, psychiatrist and neuropsychologist, 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 a diagnosis of dementia and its types.

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. In contrast to a decline in cognitive function, the patient appears in good health physically. In medical terms, it is necessary to seek evidence of 'dementia'.

A neurologist skilled in the diagnosis of dementia and its causes will often spend time taking a detailed history by talking to the family about the patient's symptoms. Next the physician will talk to the patient to determine the level of his/her intellectual function. Most often this is all which is needed to establish a diagnosis of dementia.



Doctors will sometimes administer neuropsychological tests to check various components of intellectual function. However to administer these tests a qualified neuropsychologist is required. 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 dementia 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 dementia 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.

The next step in history taking is to determine if the patient has diabetes, hypertension, high cholesterol, tobacco consumption, history of stroke or heart attack. The presence of these “risk factors” could point to the possibility of VaD in determining the cause of dementia.

Other aspect to focus on in the history to consider the diagnosis of LBD is the presence of significant fluctuation in the condition of the patient. In some cases families will report that the patient has “good days and bad days”. Also the patient may have hallucinations in which they imagine seeing things such as water on the ground or snakes in their houses. This can be very distressing to the patient. The patient can have repeated unprovoked falls and fainting attacks. These can be very dangerous and lead to hip or spine fractures. These features can lead the doctor to consider the diagnosis of LBD.

With the emerging concept of FTD, doctors will ask for the family history of any kind of dementia. Also the presence of speech and language disturbances and changes in the personality of the patient.

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 dementia 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 dementia are met.

Step 3: In differentiating the cause of the dementia, it is important to first exclude other causes of loss of intellectual function. For this purpose, doctors will conduct a comprehensive medical, neurological and neuropsychological examination (if needed). 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 AD, CT and MRI scans show a shrinking of the brain. This is medically referred to as “cortical atrophy”. In LBD, there is atrophy of the brain similar to AD. In FTD, atrophy is most marked in the frontal and temporal parts of the brain. In VaD, there are multiple strokes seen on CT and MRI.

The final diagnosis is based on history from the family, examination of the patient, neuropsychological tests, blood tests and radiology.

CHAPTER 7: RISK AND PROTECTIVE FACTORS FOR DEMENTIA

Risk factors are those conditions which increase the likelihood of a person getting the disease under consideration. Protective factors are those conditions which reduce the likelihood of a person getting the disease. These factors are generally not individually causative or protective but are usually predisposing or there are complex interactions between factors. Factors can be non-modifiable or modifiable.

Non-modifiable risk factors

Age

Dementia primarily affects older people, but as mentioned before, it is not “an inevitable consequence of ageing”. A recent report jointly published by Alzheimer Disease International and WHO, suggests that nearly 8 million people develop dementia annually. In 2015, dementia affected more than 47 million people worldwide and it is estimated that with ageing of the global population, there would be 75 million people with dementia by 2030 and 132 million by 2050. Nearly 60% of people with dementia live in low and middle-income countries and 71% of new cases of dementia will occur in these countries.

Gender

It is generally believed that men and women are equally at risk of dementia. 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 life expectancy 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 dementia 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 dementia has a higher chance of his wife taking care of him at home.

Genetic factors

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

Specifically for AD, three genetic defects considered as "causative genes" have been identified. 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 AD. These genetic defects manifest themselves by aggregation of multiple cases of AD within families affecting multiple generations. However, it must be emphasized that the proportion of all cases of AD which are inherited on a genetic basis is less than 1%-2% of all known cases of AD.

As mentioned previously, FTD have a greater proportion of cases with a positive family history of dementia. The complex inheritance pattern of different sub-types of FTD remains to be determined.

Another mechanism of genetic effect is the inheritance of a “susceptibility gene” for AD. 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 AD; there are numerous patients who have this gene and do not get AD, while there are numerous patients who do not have this gene and yet get AD. Researchers believe that external factors must interact with this susceptibility gene to precipitate AD. 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 AD in the West. This is a subject of intense research and remains to be proved.

Ethnic differences

Scientific publications in 1998 and 2001 were the first reports which showed that the prevalence and the incidence of AD were substantially lower in the Ballabgarh (Haryana, India), population compared to a population in Pittsburg, USA. This held true even after correcting for factors such as life expectancy. At that time the authors had hypothesized that the reason was an interaction between genetic predisposition and low cholesterol levels in the Ballabgarh population.

Interestingly, the February 11, 2016 issue of the Journal of the Alzheimer Association published an article which showed that the incidence of dementia was the lowest in

Asian Americans compared to other ethnic groups within the US (African Americans, Latinos and whites). This study supports the findings of 1998 and 2001. These interesting observations however, need to be explored further.

Modifiable risk factors

Perinatal health

Health of the mother during pregnancy can affect the unborn baby and the consequences can be seen even late in life during old age.

Several maternal factors in pregnancy (tobacco use, alcohol use, or illicit drug use by the mother) can adversely affect the foetus. Similarly some medical diseases such as hypothyroidism, and uncontrolled diabetes can affect the unborn child. Also appropriate maternal nutrition promotes healthy foetal development. Folic acid supplementation reduces the risk of neural tube defects. Delivery by a trained birth attendant or in a hospital reduces the chances of birth complications.

Conditions around early foetal life and the first two years are important for determining final brain size. Researchers have used head circumference (which is a widely recorded birth parameter) as an indicator of brain maturation at birth and dementia in later life. Similarly leg length of the baby is used as an indicator of nutrition in utero.

Most countries in the region have programmes for promotion of maternal health. Greater emphasis on maternal health particularly in rural areas, will contribute to mental well-being in later life.

Education

Mortimer in 1988 first suggested that years of formal education may raise “the intellectual reserve” in a person and this may protect from dementia in later life. Since then a large number of studies have consistently reported that education is protective against development of dementia in later life. The risk reduction was estimated to be 40% in a multi-centric study which included some developing countries (10/66 project). However, in the older age group who are at risk for dementia in Member States of the Region, an important question is whether formal education can be equated with skills such as in agriculture or other vocational activities. This has never been studied formally.

The multiple benefits of education, besides protection from dementia in countries of the Region with a focus on education, will be apparent in future.

Depression

WHO data suggests that depression is common among the elderly. It causes substantial disability (sometimes leading to suicide) and is frequently not recognized or treated. Recent studies have reported that depression in later life increases the risk of dementia by 1.8%. Often the presentation of depression mimics dementia. Depression is sometimes called “pseudodementia” i.e. it appears like dementia but is not.



The cultural norm in South-East Asia has been care of the elderly at home often in a joint family setting. This arrangement provided not only good care for the elderly, but also intellectual stimulation. However, the disappearing

culture of joint families or migration of the young leaving behind the elderly may adversely affect the elderly in future and increase the risk of dementia.

Smoking

The numerous adverse effects of tobacco smoke on health are well documented. With regard to the brain, tobacco smoke damages the blood vessels. Smoking has been linked to strokes which can lead to vascular dementia. Moreover, tobacco smoke increases oxidative stress and inflammation in the brain.

Recent studies suggest that current smokers compared to those who have never smoked have a higher risk of dementia. The studies also found that ex-smokers have the same risk as those who have never smoked. This is an encouraging finding, that by quitting smoking, besides other health benefits, the risk of dementia can be reduced.

All the research studies have focused on cigarette smoking. In South-East Asia there are other forms of tobacco consumption (hookah in which tobacco smoke is filtered through water, hand-rolled bidis or oral tobacco). The effect of consumption of these forms of tobacco has not been adequately studied.

Alcohol consumption

There are numerous well documented adverse effects of alcohol consumption (alcohol consumption and road traffic accidents, alcohol and poverty, alcohol and its adverse effect on the family, alcohol consumption by pregnant women).



However, there is no definitive evidence of the benefit of drinking “a glass of wine” every day and the risk of dementia. Moreover, in some South-East Asian countries the pattern of alcohol consumption, particularly in lower socio-economic strata is to drink to intoxication (binge drinking). This is a particularly deleterious pattern of drinking, linked to numerous adverse effects.

There is no “safe” level of alcohol consumption. Harm from alcohol is context related and not quantity related. For example a pilot cannot have any alcohol for several hours before flying a plane, but another person having a glass of wine with dinner, may not be adversely affected.

Physical activity

There are many well documented benefits of physical activity (lowering blood pressure, lowering blood glucose, reducing obesity, improved lipid profile, etc.). Also, brain structure and function is enhanced.

Some research studies have suggested that physical activity may be associated with up to 40% reduction in dementia risk.

The concept of physical activity relates to urban populations. What has not been adequately researched is the risk of dementia in people, particularly in rural areas, who are engaged in daily physical activity, for example, agricultural workers.

Cognitive stimulation

Research has consistently shown that cognitive activity is beneficial for both brain structure and function. Thus people should be encouraged to work in their businesses as long as they can. Also, activities like Sudoku or crosswords can stimulate the brain.

Vitamin supplementation

- *Vitamin B*

Vitamin B1 (thiamine), B6 (pyridoxine), B9 (folic acid) and B12 (cyanocobalamin) are all linked to the health of the brain and nerves. When folic acid or B12 are deficient, homocysteine level rises. High levels of homocysteine are linked to strokes and poor cognition.

- *Vitamin E*

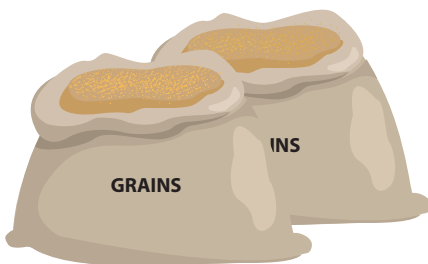
Some studies suggest that vitamin E acting as an antioxidant may protect the brain from damage by toxic substances (free radicals).

- *Omega 3: (polyunsaturated fatty acids)*

Omega 3 PUFA cannot be synthesized by the body, but are important throughout life from before birth to older ages. Dietary supplements are suggested for well-being of the mind.

Mediterranean diet

This consists of a diet high in cereals, fruits, fish, legumes and vegetables and low in red meats. Such a diet has been linked to numerous health benefits, including cardiovascular disease, type 2 diabetes, some forms of



cancer and overall reduced mortality. Indirectly it is believed to protect from dementia.

High blood pressure (hypertension)

There is strong evidence of the association of mid-life hypertension and the occurrence of dementia in late life, including risk of vascular dementia.

Midlife obesity

Midlife obesity increases the risk of dementia by 1.6 times. Some studies suggest central obesity in midlife (waist circumference) is more important as a risk factor for dementia. This has also been implicated with high risk of heart attacks in young people in South-East Asia.

High levels of cholesterol

High midlife levels of cholesterol increase the risk of stroke and maybe dementia.

Diabetes

Diabetes in late life is linked to subsequent onset of all forms of dementia particularly vascular dementia.

CHAPTER 8: CAREGIVERS AND CARING



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

In the cultural context of Member States of South-East Asia Region, care of a person with dementia is best provided by lay caregivers. These lay caregivers should be specifically trained in patient care. They must understand what dementia is, and what the patient is capable or incapable of doing. Ideally, continuity of care by the same caregiver is desirable, but this may not be practical. The “fatigue factor” of caregivers also needs to be taken into consideration. Immediate family members should be available to extend psychological support and supervision of lay caregivers. 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 are usually willing to take in persons diagnosed with dementia. Since the patients are looked after by their families until the time of death, there is a tremendous need for the education of caregivers and other forms of support. Without this, there is a high risk of patient neglect or even abuse.

Management of patients with dementia

While there is no specific cure for any type of dementia, there is a need to look after the patients as well as their caregivers. 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 dementia, 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 dementia, 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 caregivers, 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 dementia, 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 non-governmental 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 AD and other dementias. 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 countries of the Region, the basic responsibility for management of the patient rests with the family.

Some suggestions for care of a patient with dementia

Daily routine

As soon as a diagnosis of dementia 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 'sun-downing'. 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, 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.

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 winter. 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. The availability and use of adult diapers is very useful.

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 appears, 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. All floor covering must be firmly secured.

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 dementia 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 a normal person 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 and emotions

Some patients of dementia have abrupt changes in their moods and emotions (particularly those with Lewy

body dementia). 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 patient of their childhood is played, the pleasant associations put them in a nostalgic mood. This strategy is called “attention diversion”. If mood, behaviour and emotions are distressing to the patient and family, the doctor may prescribe some medications, such as tranquillizers, to calm the patient.

Wandering

Patients of dementia 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 or just lying down during



the day should be avoided. Sleeping pills are best avoided as their effect is temporary and frequently unpredictable in patients of dementia. Causes of discomfort at night, such as pain, uncomfortable room temperature or prostate trouble, should be checked.

Behavioural approaches to agitation may also address sleep-wake disturbances, including insomnia, by focusing on establishing and maintaining consistent sleep and wake times as well as incorporating more exposure to natural, bright light during the early part of the day.

Some non-pharmacological treatments

Increasing evidence suggests that a variety of non-pharmacological measures can be effective in reducing agitation and anxiety in patients with dementia. Evidence for their efficacy comes mostly from western literature. Also their application in less resourced countries is limited.

A 2014 review of non-pharmacological interventions for agitation in dementia were the implementation of simple activities in which the patient can participate, music therapy, and person-centered communication skills training for caregivers. For the most part, there is evidence of short-term but not long-term benefit.

Behavioural interventions employ different strategies and techniques. These include identifying any preceding events that generate agitation, determining whether unmet needs can be anticipated and alleviated, and avoiding environmental triggers such as a sudden change in surroundings.

Other non-pharmacological therapies include:



- Aromatherapy is safe and well tolerated. Lemon balm or lavender oil are most frequently used and can be delivered by either inhalation or skin application.
- Exercise training in combination with caregiver education may improve outcomes in patients with dementia. Regular physical activity can be useful in managing behaviours in some patients with dementia.
- Pet therapy also has some evidence of efficacy.
- Sensory interventions such as massage and touch therapy appear to be potentially beneficial in the immediate management of agitated behaviour and in encouragement to eat.

In addition to these formal activities, caregivers can be counselled in strategies involving distraction and redirection, structured routines, and providing calm, reassuring responses when patients seem anxious.

Medical treatment

A knowledgeable and understanding general physician who has the time and willingness to care for patients of dementia 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 practicing 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 dementia 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, caregivers 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.

Specific medical treatment for types of dementia

Alzheimer Disease (AD)

Unfortunately, no cure for any type of dementia has been found. However, during the last few years cholinesterase inhibitor drugs which alleviate the clinical features and promote daily activities, at least to some extent and in some patients, have become available. In AD, 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 AD. 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. These medications are still in use.

Vascular Dementia (VaD)

The most important aspect of treating vascular dementia is the control of risk factors for stroke (i.e. diabetes, hypertension, high cholesterol, cessation of smoking) and administration of anti-platelet medications. Every effort should be made to prevent recurrence of strokes.

Lewy Body Dementia (LBD)

Some experts report very good results particularly in diminishing the occurrence of hallucinations with memantine. Precautions against falling are critical. Use of inappropriate medications should be avoided.

Frontotemporal Dementia (FTD)

This being a group of conditions, symptomatic treatment particularly for behavioural problems with mild anti-psychotic medicines is recommended.

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 which claim to be effective for abnormalities or loss of intellect in old age. Proof of efficacy of these medicines 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 are 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

Ginkocer biloba is a plant, an extract from which is being researched for treating patients with mild and moderately severe dementia, but contradictory results have been reported. The basis of its action is not clearly known. Some authorities speak well about the efficacy of selegiline hydrochloride, but additional 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 antipsychotic medication haloperidol and thioridazine, probably because of side-effects. Patients with LBD are particularly prone to adverse 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. Quetiapine is helpful in dealing with agitation. These anti-psychotic medications are useful in controlling abnormal behaviour, such as sexual misdemeanours, agitation or sleep disturbances. A competent psychiatrist can effectively deal with many psychiatric symptoms in affected individuals.

Nursing care

Nursing care for patients of dementia is most important, whether at home, in an acute hospital environment, a daycare centre or in a long-term stay institution. Caregivers must be trained to promote the patient's remaining intellectual abilities; help them maintain their independence in attending to their usual functions and 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 dementia and thus provide help to families looking after affected members. Such programmes are cheaper to initiate and ease the burden of harried families.



Psychotherapy

Conventional psychotherapy is not offered to patients of dementia, 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. Behaviour modification 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 States 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 dementia, needs to be shared by NGOs as well as governmental agencies.

Home care, institutionalization and rehabilitation

Patients afflicted by dementia 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 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 dementia, 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 immigrated 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 caregivers. Experience in developed countries suggests that 95% of the care is provided by the family members themselves and among them, the spouse (often elderly themselves) 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 caregivers, 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 dementia in personal care (bathing, dressing, and feeding) or in providing instrumental care (shopping, transportation, and 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 good 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 at least the basic minimum facilities. These are cost-effective alternatives to nursing home care and to delay admission to long-stay institutions.

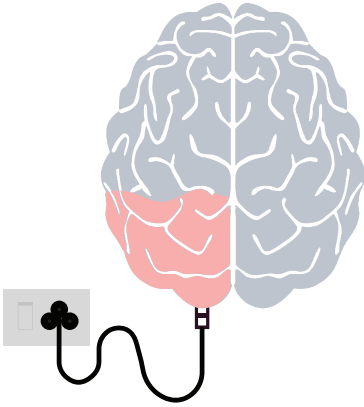
Respite care

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 caregivers 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 States of the Region for patients who are at an advanced stage of dementia. At the same time, delegating care of all patients to special care homes for patients of dementia, 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.

CHAPTER 9: WHAT CAN BE DONE



What the patients can do for themselves

With the available understanding about the causes of dementia, nobody can guarantee that he or she or their loved ones will not get any kind of dementia. 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, everyone should practice 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 dementia, 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 dementia.

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.

A healthy lifestyle consisting of a balanced diet, some vitamins, physical activity, cognitive stimulation and not smoking all have a potential to promote brain health and perhaps protect from dementia. The association between correctable and treatable factors (diabetes, hypertension, high cholesterol, obesity) gives some optimism for reducing the occurrence of dementia in late life.

Some strategies for which there is scientific evidence for promotion of brain health and protection from dementia are given in the table on the next page :

Promotion of Brain Health
Yoga and meditation
Control of high blood pressure
Control of blood sugar
Control of high cholesterol
Stop consumption of tobacco
Stimulate the mind (Sudoku, crosswords)
Assess mood (overcome depression)
Supplements of <ul style="list-style-type: none"> • Vitamin D • Vitamin B12 and folate • Vitamin E • Omega 3 fatty acids
Mediterranean diet
Mid-life obesity
Moderate exercise
Cardiorespiratory fitness
Avoid excess alcohol



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 dementia. 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 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 dementia carry a huge burden of caring and need the support of neighbours and the community. Neighbours can also provide respite care to the tired caregiver.

Special training programmes for lay caregivers can be organized in the community. These lay caregivers need not be qualified nurses, but individuals with empathy. They must be trained in specially designed courses usually conducted by NGOs. The basic contents of the course should include basics of understanding dementia, what the patient can do and what the patient cannot do and

how best to care for the patient to give relief to the family. Awareness campaigns can be launched by community activists to educate those who may not be aware of this disease and its early manifestation.

What national governments can do

Most countries in the South-East Region of WHO do not as yet have a specific policy on dementia control, but all countries have programmes on noncommunicable disease control. As noted in the chapter on risk factors, most of the factors are common to dementia and noncommunicable diseases.

The only additional action required of governments is to make dementia a measurable end point in the noncommunicable disease control programmes. Specific programmes which are already being implemented include:

- Maternal and perinatal care
- Universal education
- Hypertension control through salt intake control
- Diabetes control
- Cholesterol control and obesity control particularly among the youth
- Tobacco control
- Opportunity for work/life balance
- Opportunity for yoga, meditation and spirituality
- Care programmes for those with dementia.



What WHO can do

WHO operates at three levels: global, based in Geneva, six regional offices and national offices in each country. Specific activities are conducted at all three levels as appropriate.

- Continued advocacy to raise awareness and understanding of dementia worldwide.
- Information and surveillance through the Global Dementia Observatory.
- Service development for care of people living with dementia and their families.

CHAPTER 10: GOOD NEWS

The number of older adults will increase around the world in future decades as populations age. It is expected that the worldwide prevalence of dementia will triple to 132 million by 2050.

However, a number of recent population-based studies from countries around the world suggest that the age-specific risk of dementia may be declining, which could moderate the expected increase in dementia cases in the growing older population in future.

Most of the studies documenting the decline in age-specific risk of dementia over the past 25 years have been done in developed countries (USA, UK, The Netherlands, Sweden and Denmark). The studies have estimated that about 3% of worldwide cases of dementia are due to diabetes, 5% due to hypertension and 13% due to physical inactivity. The factors hypothesized to be contributing to this decline include rising levels of education, better treatment of vascular risk factors (hypertension, diabetes, high cholesterol and declining levels of smoking).

The key questions are to watch the effect of increasing levels of obesity and diabetes both in the developed and developing countries. Moreover there is very little emphasis on control of vascular risk factors in developing countries, such as rampant obesity among youth, which in future will account for a majority of patients with dementia.

The other important worldwide trend over the last 25 years has been the increasing level of educational attainment, both in developed and developing countries. An explanation for the benefit of education is the

“cognitive reserve” hypothesis by which education develops additional neural circuits thereby protecting people from dementia. Education may have some indirect benefits e.g. engaging in stimulating and less hazardous occupations; indulging in less health damaging behaviours such as obesity or cigarette smoking; participating in health promoting behaviours such as increased physical activity and regular medical check-ups in which vascular risk factors may be detected and treated.

The additional good news is that of the ethnic groups recently studied in the USA, Asian Americans have the lowest risk of dementia. This finding when combined with other reports of unique characteristics of Asian populations (increased predisposition of allergy to carbamazepine and oxcarbazepine) and LBD being the commonest type of dementia suggests the need to determine what protects the Asian communities. The reasons for this protection when determined should be promoted and adapted by other communities.

REFERENCES

1. What is dementia?

Diagnostic and Statistical Manual 5. The American Psychiatric Association 2013.

2. What are the causes of dementia?

<http://www.mayoclinic.org>

3. What is Alzheimer disease?

McKhann GM, Knoopmam DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement* 2011May;73(3):263-9.

4. What is vascular dementia?

Jellinger KA. The pathology of "vascular dementia": a critical update. *Journal of Alzheimer's Disease JAD* 2008;14(1):107-123.

5. What is Lewy Body Dementia?

McKeith IG, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies. *Neurology* 2017;89:88-100.

6. What is Frontotemporal dementia?

Coyle-Gilchrist ITS, Dick KM, Patterson K, et al. Prevalence, characteristics, and survival of frontotemporal lobar degeneration. *Neurology* 2016;86:1736-1743

7. Are there unique characteristics of dementia in India?

Chandra V, Mehta VS. Distribution of types of dementia in first 100 patients seen at a dementia clinic in India. *Journal of Alzheimer's Disease* 59(2017):797-801.

8. What are some risk and protective factors for dementia?

World Alzheimer Report 2014; Dementia and Risk Reduction.

9. What is a "Living Will?"

<http://www.patientsrightscouncil.org>

10. Is the occurrence of dementia declining in some communities?

Langa KM, Larson EB, Crimmins EM, et al. A comparison of the prevalence of dementia in the United States in 2000 and 2012. *JAMA Intern Med* 2016; Epub 2016 Nov 21.

11. Are there variations in the risk of dementias in different ethnic groups?

Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement* 2016 Mar;12(3):216-224.

Why This Document?

Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour that interfere significantly with a person's ability to maintain the activities of daily life. In 2015, dementia affected 47 million people worldwide, and is predicted to increase to 75 million in 2030 and 132 million by 2050. Dementia has several implications for South-East Asia Region, nearly 60% of people with dementia currently live in low- and middle-income countries (LMICs) and the majority (71%) of new cases is also expected to occur in LMICs. Evidence shows nearly 90% of people with dementia in LMICs do not receive any diagnosis, treatment or care. This publication on dementia is focused on improving dementia awareness, reducing stigma and accelerating focus on risk reduction by promoting a better understanding of dementia, including respect for human rights of people living with dementia.