

## Forgetfulness : Is It a Disease?

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It is quite natural to be forgetful at times. Can such a common thing be a disease? In fact, our brain is programmed in such a way that forgetfulness is nothing unusual. It is basically a process whereby we filter out unnecessary information from our brain. We are choosy about storage of information and, with age, we become choosier; so this filtering out is a normal process of the brain. As human beings, we focus not on remembering but on understanding what we see around us.

The normal mistakes can be avoided by following certain things religiously and consistently, by (a) using reminders; a phone or a diary may be used to keep reminders; (b) being organized. This means to work in a disciplined way. If we keep our things in a messy way, we face problems in finding them; (c) eating well. Apart from being nutritious, the quantity of food and eating time also matter; (d) exercising. Physical exercise keeps one mobile, thus helping not to forget; (e) good sleep. This is absolutely necessary to keep you healthy.

Causes of forgetfulness can be divided into two categories:

*Non-medical* which includes attitude, lifestyle and fatigue. Attitude is very important to retain information. Some of you attending to this lecture might not be able to recollect what you are hearing now. This is not because the capacity of your brain has decreased. Maybe you are now thinking about something else. Lifestyle includes exercise and food habit. And then fatigue. According to memory specialists,

it is creating a lot of forgetfulness and memory issues in people.

*Medical* which includes depression, brain injury and dementia. Among these three, we shall discuss dementia in detail.

### Symptoms of dementia

Dementia is a gradually increasing problem in India. Doctors use this term if they find certain symptoms among the patients. The symptoms are (1) recent memory loss that affects job skill, (2) difficulty in performing familiar tasks, (3) problems with language, (4) disorientation with time and place, (5) problems with abstract thinking, (6) poor or decreased judgement, (7) misplacing things, (8) change in mood or behaviour, (9) change in personality, and (10) loss of initiative.

Doctors declare a person to have dementia if they find 5-6 of the above symptoms. Brain too gets sick like other parts of the body. This leads to brain damage and a number of symptoms arise due to this. Hence, dementia is not a specific disease. It is an overall term that describes a group of symptoms associated with a decline in memory or other brain functioning severe enough to reduce a person's ability to perform everyday activities. It is caused by physical changes in the brain.

Being unable to recall minor issues like not finding a particular item, say in a room, is not dementia. But if, after entering a room, one can't make out where he/she is, then it is to be considered as dementia.

Statistics reveal that there are 55 million people suffering from dementia in the entire world. This has been divided among 10 countries where India is in the 2nd position (8.8 million) next to China. We were in the 3rd place nearly one and a half year back and have been promoted to 2nd position on 22 December, 2022. One reason is that since the advancement of medical science has increased our lifespan significantly, the number of elderly people is also increasing gradually and the number of youngsters is declining. A recent study by AIIMS-Delhi and University of Southern California showed that the number of 8.8 million dementia-affected people in India may increase to 17 million by 2036. They have also provided us with the statistics of incidence in different states of India. The number is maximum (11.04%) in Jammu & Kashmir, and the minimum in Delhi. It is a matter of great concern as to why the number is so high in Jammu & Kashmir. It may be because of the turmoil they have gone through. In West Bengal also we are not way behind, it is 9.23%. We are really concerned as to how to prepare ourselves as a society, as a community to help those people.

Statistics show that a dementia case is diagnosed anywhere in every 3 seconds. This means a fully mature brain is getting damaged in every 3 seconds whereas, with every new birth, we get a new brain in every 8 seconds. Another alarming thing is that in the entire world, two out of three persons do not have any clear idea about dementia. Majority of people think dementia is forgetfulness. This conception is entirely wrong and we are to make them aware of it.

Dementia can affect anyone from any sphere of life. It is not a normal part of ageing though it is more common in people over the age of 65. Early onset of dementia can begin in 30s, 40s or 50s. Dementia

affects mental health but it is *not a mental illness*. It is a progressive brain disorder.

### **Some challenges**

We, the professionals working in this field, are facing some challenges. We are normally more concerned about the problems with our body parts that are below the neck. We have no problem in visiting a doctor for our knee pain, back pain or when we face any difficulty in moving one hand. But for any complication in the part above the neck, we try to solve it ourselves or don't disclose the problems. So, there is a low awareness of brain health and little brain-health-seeking behaviour.

Detection of dementia is based on a scale. India being a country of diversity, the professionals working in this field are struggling to come up with one scale. A person can live long with dementia. There is a high care cost of looking after the person as well as the medication. Even more challenging is the fact that the professionals who come to look after the patient don't have proper training beforehand. In India, practical training is more important than the theoretical one. Another problem we face is the lack of a National Policy. In 2017, we presented a plan named 'Dementia Health Priority' to our Health Minister but we are yet to get any positive reply.

### **Ten warning signs**

I am now going to illustrate some of the 10 warning signs already mentioned. One warning sign is short-term memory loss. The person may find it difficult to remember the food eaten sometime back or may not recall the conversation he/she had the previous day but finds no problem in remembering the schooldays. The person also finds problems in everyday activities like bathing, brushing, etc. It develops

gradually and people around him/her mostly miss the early stage. This is because this forgetfulness is not much different from that of the normal people. That's why early detection is a huge challenge for researchers, since early detection can provide them with a specific direction.

Misplacing things is one of the warning signs. This seems to be quite common among all of us. In normal cases, we may find it difficult to remember where we had kept the key after opening the lock. But people with dementia, even after finding the key, can't just remember the role of the key. Hence, this type of forgetfulness is very debilitating.

People affected by dementia find it difficult to use proper sentences for expressing themselves. Since I have a healthy brain, I am able to communicate clearly with you. This would not have been possible with a damaged brain. Unfortunately, we are least concerned about the function of our brain. We can appreciate our brain only when we understand its different parts and their functions.

### **Two hemispheres of our brain**

Brain consists of two hemispheres—the right and the left. There are nearly 100 billion neurons or nerve cells connected with each other. These neurons function continuously and send signals from our brain which enable us to perform any type of work. There are also four lobes in each hemisphere and these are of immense importance.

Frontal lobe, the front part of the brain, plays its role when we solve problems, make plans, control our temper and use good manners. Parietal lobe is situated at the back of the frontal lobe. It is responsible for activities like paying attention, using our senses such as smell, touch and to read/

write. Parietal lobe controls all the five senses. Temporal lobe is situated on the side of the brain above the ear. This helps us to understand what we hear. Dementia-affected people don't understand what they hear. If you ask for a glass of water from such a patient, the person might give you just a blank look. This is because he/she could hear but could not follow or understand what was said. Lastly, the occipital lobe is located at the back of the head just above the shoulder. This works with our eyes and gives us the understanding of what we are seeing. Any damage in occipital lobe will stop us from making sense of what we are looking at. This is why a dementia patient cannot take decision while crossing a road.

The causes of dementia may be reversible or irreversible. Reversible are those which are curable through treatment but the irreversible type has no cure so far in the entire world. Reversible dementia can develop from brain injury, thyroid problems or vitamin B12 deficiency. In case of brain injury, one of the causes may be a blood clot in the brain and it can be removed by operation and the injured person can gradually come back to normal life. Thyroid, if undetected or untreated, may create dementia problem that is easily curable. Vitamin B12 deficiency can be easily removed by using proper supplements.

In our organization, we work with the irreversible cases. There are several causes of irreversible dementia. Here I'll discuss four major causes.

Alzheimer's disease is the commonest form of dementia. A classical symptom of Alzheimer's disease is forgetfulness. The patients can't remember the name of a known person or even the name of the place where he or she is. Basically, in this type of dementia, tau protein and amyloid plaques are deposited in the brain, thus disrupting the function of nerve cells. The reason behind this deposition

is not known and there is no remedy anywhere to bring the cells back to the original form.

Vascular dementia is most common in India. We have several heart-related problems or vascular issues. Insufficient supply of blood into the brain causes minute strokes inside the brain. As a result, the affected lobe(s) out of the four will have problem in specific functions. In this type of dementia, forgetfulness is not a major issue but it starts with the repetition of the same topic and personality change. Forgetfulness also starts as the disease progresses.

Dementia with Lewy does not have forgetfulness initially but the person's mobility is somewhat affected. This is known as 'shuffling gait' which is a type of walking where one drags the feet without lifting from the ground; hence there is always a tendency to fall down. In this type of dementia people also have the problem of hallucination or delusion. In case of hallucination, one claims to see or hear things which are not visible or audible to others. In delusion, one gets the false belief that a very familiar person has come to attack him or her or a very trustworthy domestic help working for quite long is going to steal everything.

Frontotemporal dementia starts with behavioural changes and not with forgetfulness. Very recently, we have come to know one such case where a gentleman had withdrawn a huge sum of money from bank and distributed it among various people. His family members were totally unaware of this. After nearly three years of this incident, he was diagnosed with frontotemporal dementia. Even now, he comes occasionally to our centre and offers us money.

### **Irreversible dementia**

Irreversible dementia usually goes through three stages: (a) Early Stage (Mild degree)

where the person can work independently but has difficulty in multi-tasking. This stage is normally ignored by the patient as well as the people around him or her. They think that lack of proper sleep or some other thoughts in mind might have caused the problem. At this early stage, a little more awareness is needed and this awareness can be achieved if we have a clear conception about our brain. Due to our lack of awareness, the disease is detected only in the middle stage.

(b) Middle Stage (Moderate degree) is the condition with increasing dependency, needing help with personal care and other activities of daily living. The person shows behaviour changes including wandering and aggression. At this stage, a person may commit mistakes like writing extra zeros, for example Rs. 50,000 in place of Rs. 5,000, on a bank cheque. Gradually the family members realize that the person is facing some problems and he or she becomes more dependent on others for personal care like bathing, brushing, etc.

Dipika, daughter of the founder of our organization Ms Shephali Chowdhury, had a similar problem. At that time she was working in a multinational company. On her way back from workplace by car, she would wander around her own house being unable to locate it. In this type of dementia people might also urinate in the kitchen thinking it to be the bathroom.

(c) The Last Stage (Severe degree) shows significant dependency. The person requires constant help for all activities including eating, bathing, cleaning, etc. In fact, at this stage the patient does not even remember how to swallow food as this requires brain function. They have difficulty or may be unable to communicate. These people find difficulty in recognizing relatives and friends and may not even identify themselves. Their

physical functions deteriorate and mobility decreases considerably.

It is not necessary, however, that all patients are to pass through all the three stages. Someone with comorbidity or some other problem might not enter the third stage at all. We, the professionals working in this field, give three different types of support for the three stages. Support in early dementia includes appropriate counselling, referrals and planning. There is also training to maintain privacy, dignity and autonomy of the person. In the early stage, a person feels inhibited to talk openly with others as he or she has the fear of being insulted. This time, counselling, referrals and planning can provide him or her some confidence. The surrounding people, including the near and dear ones, and even the general public usually start treating them differently and forget to give them due respect. But it is quite possible that a person diagnosed as a dementia patient today was highly established in life. Hence it is our duty to support them.

In case of moderate dementia, there are strategies to prevent behavioural and psychological symptoms and tips to safeguard their safety. At this stage, family members need counselling. Our society requires many more professionals like us who after suitable training can look after the patients properly and can also realize the tough situation faced by the patient as well as the family members. Severe dementia patients require quality nursing and palliative care. It is absolutely necessary to have appropriate use of medication avoiding both over-and under-use. Quality nursing is essential at this stage. A person who is totally bedridden does not necessarily mean that he or she has nothing left in life. Even at this stage, we can provide good support.

With the advancement in medical science, our life span has increased considerably and many of us, even if we don't have dementia,

may have to spend a long period in bed. Hence, this is high time that we started thinking and planning about the quality of life we would like to have during those days.

Compared to the normal brain, an Alzheimer's brain shrinks considerably. Gaps are created inside the brain due to large number of dead cells. The brain shrinks to such an extent that there is hardly any matter left inside.

### **Diagnosis and treatment**

What about the diagnosis? If one develops at least 4-5 dementia symptoms, the person may come to our organization with the complaint of excessive forgetfulness. We carry out one detection test that takes 15-20 minutes. Here we ask thirty very common questions like today's date, the name of the city where you are living, etc. Based on the number of correct answers, we decide on the next step, as to whether the person may continue with the normal life and need not visit us in near future. If the number is below or just above a certain minimum, the person is usually asked to come after 6 months for another test. When the number falls far below the minimum, we refer the patient to a neuropsychologist, a psychiatrist or a neurologist for detailed testing. It may not always be due to dementia as dementia-like symptoms may appear in several other cases also. The doctor takes the patient's medical history, then carries out some evaluation and may advise for brain scanning—MRI or PET scan. The report enables the doctor to locate the damaged region in the brain.

As far as treatment is concerned, till now there is no treatment in the entire world for complete cure of irreversible dementia but it can be managed. There are 3-4 medicines used for controlling the symptoms of dementia. So, the medication will not cure the disease but treat the

symptoms. Under these circumstances, when medical intervention is very limited, may be 10-15%, psychosocial intervention has a vital role to play.

A study of the history of dementia reveals that initially it was treated as a medical problem only, but from 1950 onwards, we have started noting that most of the dementia-affected people are highly talented individuals. Even if not in professional life, a homemaker used to manage her family very efficiently. From various experiments we have realized that they are able to relearn things if kept socially and psychologically active. Nowadays, researchers are working on neuroplasticity. We don't utilize the total capacity of the brain. Research reveals that only 5-7% of the brain is utilized; the rest is unused! That's why it is said—use it or lose it. So, the thing is that you have to utilize your brain.

In dementia management, the very first thing is its prevention. If the person has already been affected, the next step is proper diagnosis as sometimes wrong diagnoses are being reported. Once diagnosed, our third objective is supporting them well. Next, we are to ensure that the person and his or her family can live well. Lastly, when the person is approaching the end of life, we are to see that the person can die well. In fact, dying well does not depend on one's doctor or the family members; it's the individual who decides how he or she wants to die. We all should start thinking about it since our longevity is increasing. Death is inevitable, but we usually avoid discussion on such a touchy topic. All things have probabilities of happening but death is the ultimate reality. We want our children to stay away from this matter. But the subject of 'dying' should start in school. Everybody should be made aware of it.

### **Risk factors**

There are several risk factors for developing dementia. The factors include

(a) Age: Every year, we get older by one year. This is a natural process and we have no control over it. With increasing age, the tendency of dementia increases.

(b) Family Genetics: A history of dementia in someone's family does not necessarily mean that the person is bound to have dementia; but the chance will definitely increase by 5-6%.

(c) Gender: Global study shows that in the age group of 65-75 years, the number of reported dementia cases is more among the males. This is not because the male members are more vulnerable to dementia but the male members' cases are reported to us by other members of the family. In case of female members, they themselves suppress their cases. Of course, the number of female members is more after the age of 75 years since females live longer than males. Also, the hormonal imbalance after the age of 50 has some effect on the cognitive power of the brain.

(d) Education: It can be a protective factor specially if started from early age.

(e) Hearing Impairment: In this case, early detection as to whether the problem is of the brain or of the ear is very important.

(f) Physical Inactivity: If a person remains awake for 18 hours a day and spends 8 to 10 hours idly, he/she is inviting various problems including dementia.

(g) Lifestyle Diseases: Diabetes, hypertension and obesity are some of the risk factors for developing dementia.

(h) Infrequent Social Contact: The less we communicate face to face with our friends and relatives, the more is the harm to our brain. Contact over phone will not serve the purpose.

The other risk factors are (i) smoking and taking alcohol, (j) head injury, (k) diet lacking

in nutrition, (l) chronic use of medicine, specially over-the-counter medication. Sleep disruption, air pollution, and inadequate mental stimulation may be other contributory factors. In addition to physical activities, mental exercise is also needed. We must bring some variation in our everyday work.

#### Four pillars of prevention

There are four major pillars of prevention of the disease. First, regular exercise for 20-25 minutes every day. Sitting idle is a silent killer. In fact, our problem has started with the over-use of chair. We use chair for eating, watching T.V., chatting and what not. The more we keep ourselves mobile, the less will be the problems.

The second pillar is social engagement. One should try to meet friends and relatives at least once a week. Specially after Covid, person to person interaction has declined sharply. We should try to restore it. In Greece, a research was carried out with about 150 members in a community and the members were mostly above 70 years of age. No case of dementia was detected. This was because everyday chatting is a part of their lifestyle.

Thirdly, a healthy diet is very much needed. Lots of green, leafy vegetables are recommended. The items which should not be consumed regularly are some refined products like sugar, maida (flour), etc. It is recommended to drink plenty of water as it flushes out the toxic substances from the body.

The fourth pillar is mental stimulation. Brain can be stimulated if the same regular work be done in a slightly modified way. Those who cook regularly in their home can

cook an item in a different mode and this basically stimulates the brain. Similarly, just for a change, if a newspaper be read from the last page instead of the first page, the brain gets stimulated since the brain was tuned to reading from the first page. Even if the regular route to our everyday destination be changed slightly, the brain gets stimulated. There was a 10-year-long survey conducted on the London taxi drivers regarding their brain functioning. Their neuron connections were found to be amazing because they were not using any GPS or map. They used to utilize their brain to find the suitable route. In our country also, ordinary taxi drivers get their brain stimulation. Another 40-year-long study on the Missionary Nuns showed no cases of irreversible dementia as they maintain a highly disciplined lifestyle.

Before concluding, I'll tell you a few words about our organization which has been working since 1999. We aim at focusing our support on the person living with dementia and his or her family members. Our programmes and services include, among other things, Creating awareness, Memory Screening, Memory Clinic, Counselling, Training family members and those who want to be professionals in this field, running a Day Care, providing Home Companionship. We are also doing some nominal research work and are really interested to start it properly. In India, this type of research on caregiving for dementia patient is absolutely nil. So, anyone interested to work on this line is most welcome.

I'll conclude by saying that it is *forgetting* and not *remembering* that is the essence of what makes us human. ■

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