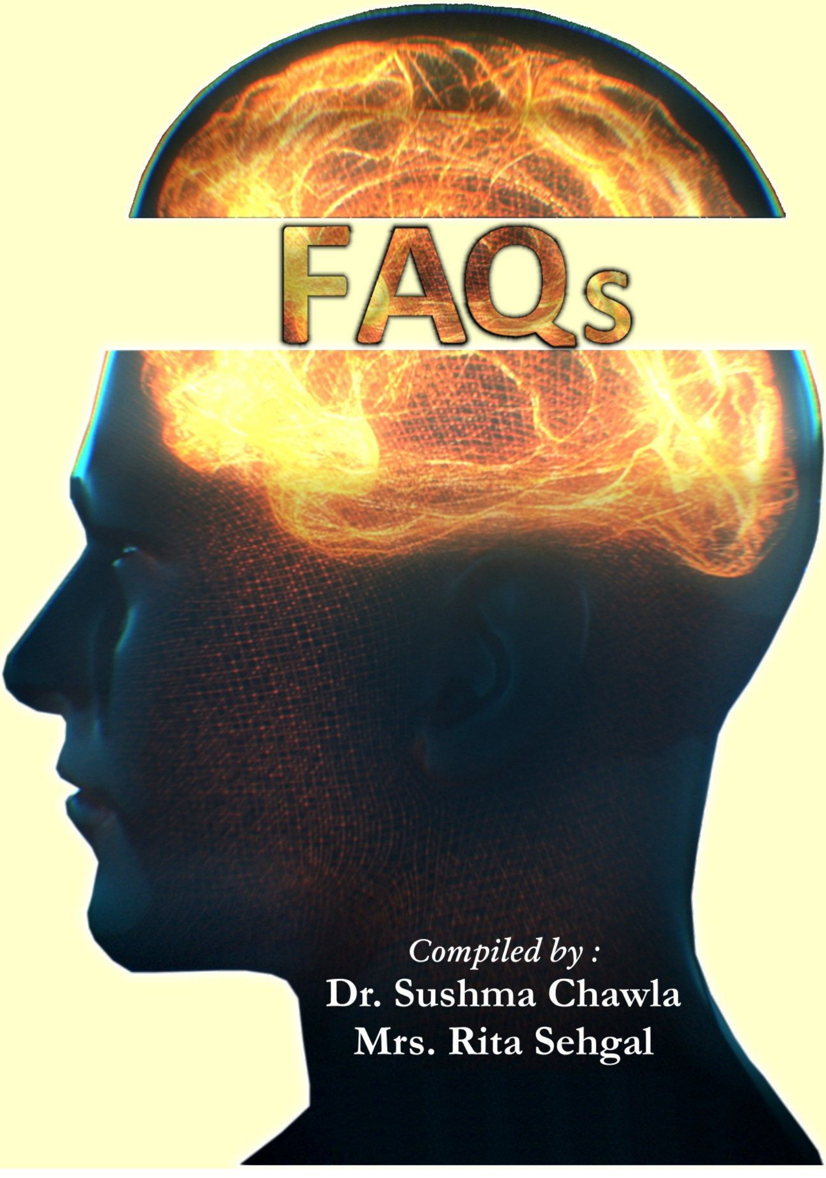
Frequently Asked Questions
of
ALZHEIMER DISEASE

FAQs



Compiled by :
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Dedicated to

Shri Satyapal Trehan Ji

Benefactor - Hope Ek A.S.H.A.

PREFACE

It is an entirely new task for me to write a preface for this handbook of "FAQs of Alzheimer Disease". The journey of Hope Ek A.S.H.A. started in the year 2000 when I lost my mother to Alzheimer Disease. While caring for her for 6 years I was always perplexed as to why my mother remembers her past so well and forgets to take bath. It was indeed very annoying and disturbing to witness the slow decline of an outstanding personality. I lost my mother before her death and it was extremely painful.

After my article in 2001 in TOI "Life in Twilight Years", I woke up to a stream of calls from the distressed caregivers. It was then that "Hope Ek A.S.H.A." was born and registered in 2001. At that time I wanted to hold the hands of these caregivers and give them solace to the best of my capacity. Slowly I was joined by volunteers, medical doctors, psychologists and caregivers. The questions, the concern, the fear, the guilt and the annoyance were the same and believe me nothing has changed over the years. We live in a society where we take care of our elderly at home and do not discuss the cognitive decline with anyone. The reason is lack of awareness and social non acceptance. The family undergoes immense mental, social and financial stress and the relationships are strained.

The thought of writing down something for the caregivers was brewing for a long time. People kept asking me and my volunteers different questions regarding the disease, the care, the prognosis and ofcourse the day to day developments. My husband suggested me to pen down all these conversations in a "Question - Answer" format for the benefit of caregivers.

AND

The Handbook of "FAQs of Alzheimer Disease" took shape and is dedicated to the caregivers of Alzheimer Disease patients.

Dr. Sushma Chawla
(Founder President)
Hope Ek A.S.H.A.

ACKNOWLEDGEMENT

I thank the Almighty who gave me strength to write this handbook “FAQs of Alzheimer Disease”.

It could not have been possible without the immense support and relentless efforts of Mrs. Rita Sehgal - Editor and Joint Secretary - Hope Ek A.S.H.A, who has been associated with this society for the last 12 years as a volunteer and a counselor to the caregivers of Alzheimer disease patients and Mrs. Benu Bhargava - Joint Editor of HEA and a volunteer with Hope Ek A.S.H.A

The caregivers and the families of the AD patients who have been caring tirelessly for their loved ones with dedication and compassion and are associated with Hope Ek A.S.H.A. for years now. The concern and inquisitiveness of the family members of the Alzheimer Disease patients motivated me to pen down this book.

My beautiful family of my husband and my children who keep encouraging me all the time. They are my best critics. My grandsons Nalin & Yuvan are the source of my energy and inspiration.

FOREWORD

As the longevity is increasing so is the prevalence of Alzheimer Disease. Dr. Sushma Chawla has brought out the book FAQs of Alzheimer Disease, which is apt and timely. It has important contribution as it enhances the knowledge not only of the common man but also of the caregivers. The complex topic has been handled in very simple way and easy language.

It is a must read as family members can learn the simple tips to solve the daily hassles. It also deals with caregivers' anxiety as they go through emotional. physical and financial problems. It covers all the areas of concern.

I would like to congratulate Dr. Sushma Chawla for her compassion and comprehensive understanding of the problems faced by the family members, caregivers and geriatric population.

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CONTENTS

FAQs
of
Alzheimer Disease

Q. 1. What is Alzheimer Disease?

Ans : Alzheimer disease is a neurodegenerative disease. It is a disease of the brain that causes problems with memory, thinking and behaviour. It slowly erodes the brain leading to memory loss, confusion, impaired judgement, personality change, disorientation and inability to communicate. Alzheimer is irreversible and manifests commonly after 65 years of age.

Q. 2. The term Dementia is sometimes used instead of Alzheimer. Are these two names for the same disease?

Ans : Alzheimer disease is the most common type of Dementia. Dementia is a term used to describe various disorders of the brain that all results in progressive and severe loss of memory that eventually makes it impossible for the sufferer to perform even the simplest everyday tasks without help. In simple language Dementia is an umbrella term for a variety of diseases and conditions that develop when nerve cells in the brain no longer function properly.

Q.3. What are the possible causes of Alzheimer?

Ans : At the moment, diagnosing Alzheimer remain an imprecise science. A lot of research is being done in this area, a great deal still remains to be discovered about why people develop Alzheimer. We know that the changes in the brain leading to Alzheimer are associated with ageing, but also that, they are not a part of normal ageing process. We don't know what factors trigger the characteristic changes that occur in the brain tissues of people who have Alzheimer Disease. In some cases, the changes occur at a relatively early age too.

Genes are believed to contribute only to a person's susceptibility to the disease. Claims that stress or worry causes Alzheimer Disease or it is caused by over use or under use of brain, or Aluminium in diet are not widely accepted by experts.

Q.4. I am 60 years old and about to retire in a few months. I have difficulty in recalling names. Am I heading towards Alzheimer disease?

Ans : Having difficulty in recalling names does not mean that you are heading towards Alzheimer. When we are about 60, we feel that our memory is not as sharp as it used to be. For example we have difficulty remembering names, things that we were going to buy or sometimes what we were going to do. We also forget dates. This does not mean we are getting Alzheimer Disease. A person who is ordinarily forgetful can still remember details associated with things he has forgotten. For example, he may simply forget the name of his next door neighbour but still knows that the person to whom he is talking to, is his neighbour. Whereas an Alzheimer patient forgets not only the details but the whole context and may also have other problems like changes in behaviour and loss of ability to do everyday tasks. In people who have Alzheimer, their short term memories disappear completely. Still, if memory problems are seriously affecting ones daily life, it could be early stage of Alzheimer. So one should consult a doctor.

Q. 5. How does Alzheimer disease usually progress? Does Alzheimer Disease differ from one person to another?

Ans : No two people with Alzheimer disease will follow exactly the same course. In some people it may progress rapidly with extreme severity whereas in another it may progress slowly and mildly. The disease progresses gradually and does not fit neatly into the three stages of its development mentioned below. These stages serve as a rough guide to the progression of Alzheimer and help carers to be aware of potential problems and to make plans for future care needs.

STAGE 1 :

- Recent memory loss is prominent but past memory is very well retained. Patient finds it difficult to remember recent events, date, month, year or important names.
- Gets lost in familiar places.
- Faces difficulty in managing finances, going for shopping or making regular dinner or misses important doctor visit etc.
- Poor judgement and delay in decision making.

- Confusion increases and there is disorientation of time and place.
- Language difficulties : Finding the right word or phrase may become almost impossible. At this stage the patient may stop talking to avoid embarrassment of making mistake or may ask the same questions repeatedly.
- He may also cover up the shortcomings by smiling or nodding.
- Loss of initiative and mood swings are very common. They loose interest in reading a news paper, watching TV or going for a walk and become very passive.

STAGE 2 :

As the disease progresses and more nerve cells in more parts of the brain are affected, the person with Alzheimer may exhibit more personality changes.

- May need help in basic hygiene.
- Poor judgement that poses risks such as wandering and falling may occur. Sometimes patient might get lost.
- Confusion over the identity of familiar objects and people such as thinking of his wife as his sister.
- May make up stories to fill up gaps in memory.
- May accuse loved ones and family members of illicit acts that never occurred.
- May exhibit-in-appropriate sexual behaviour such as disrobing in public or masturbating in front of others.
- Unprovoked aggression is marked.

- Has increased difficulty with speech.
- May experience hallucinations.
- May become extremely dependent and might constantly follow the carer in the house.

STAGE 3 :

In this stage the patient's personality is entirely changed and requires total assistance for all activities of daily living.

- Complete memory loss and no longer recognise self or close family members.
- May refuse to eat, chokes or forgets to swallow.
- Looses control of bowel and bladder.
- May have seizures and experience frequent infections and falls.
- Walking becomes unsteady. May be too weak to stand alone unassisted.
- May groan and grumble unprovoked or cry repetitively.
- Speech becomes increasingly incoherent to understand.
- In some cases the person may become bed-ridden.

Q.6. What kind of memory loss is an indication of Alzheimer disease?

Ans : Alzheimer affects a person's behaviour, cognitive function and personality in many ways. Below is the list of some changes one might see in a person heading towards Alzheimer.

- Misplacing things in odd places like putting a wallet in the freezer, wrist watch in a sugar bowl.

- Repeating the same phrases or story over and over again with no awareness of repetition.
- Taking longer to do routine chores and becoming upset if something unexpected occurs.
- May forget to eat, eat only one kind of food or eat all the time.
- May neglect hygiene and wear same clothes day after day while insisting they are clean.
- May become obsessive about checking, searching or hearing things of no value.
- May find difficulty in planning, decision making and problem solving.
- Withdrawal from family work and social activities will be visible. May sleep more than usual.
- Inability to concentrate and extreme mood change are felt.
- Abstract thinking becomes increasingly difficult. It becomes hard to do things that involve multiple steps, sound reasoning and judgement. They may make choices and decisions that are faulty or even dangerous.

Q.7. Both my parents suffered from Alzheimer disease. Am I also at the risk of getting this disease?

Ans : No one knows exactly what triggers the disease process in Alzheimer but most experts do agree that genetics play a role.

Familial Alzheimer Disease (FAD) or Early Onset of Alzheimer is an inherited, rare form of disease, affecting less than 10% of Alzheimer Disease patients. It develops before the age of 65, in people as young as 35. It is caused by one of the three gene mutations on chromosomes 1,14 and 21. If even one of these mutated genes fis inherited from a parent the person will almost always develop FAD. All the siblings in the same generation have a 50/50 chances of developing FAD if one parent has it.

In these circumstances one can go for a genetic test but the disadvantage of the test is that if it shows you do have the gene you may find it hard to cope up with the thought that you will develop a disease with no cure.

But just because a family member has Alzheimer doesn't mean you'll get it. It only means that your chances are higher than the next person who has no relative with Alzheimer.

Q.8. I am a 55 year old female - depressed, lonely and experience loss of interest in any activity. Am I heading towards Alzheimer disease?

Ans : There is no evidence that stress, worry or loneliness is responsible for causing Alzheimer. However depression can lead to forgetfulness and confusion that may sometimes be mistaken for early Alzheimer.

As the symptoms of depression are so similar to those of early Alzheimer Disease, it's often difficult to distinguish one from the other or to determine whether the person has both the conditions. Case studies have reported that people who report more depressive symptoms were more likely to develop Alzheimer. If people with Alzheimer become depressed they often cannot express feelings in words and they are not sensitive to the moods of people around them. Alzheimer itself does not respond to treatment with anti-depressant drugs.

The key is to consult a doctor to identify depression and to treat it as soon as possible.

Q.9. I am a Diabetic with a family history ofDiabetes. Am I at a risk of developing Alzheimer?

Ans : These days a large number of people are Diabetic. It is a disease that makes the body less able to convert sugar to energy. When diabetes is not controlled, too much sugar remains in the blood. Over a period of time this can damage organs, including the brain.

Scientists are finding more evidence that could link type 2 Diabetes with Alzheimer disease. Several research studies suggest that adults with type 2 diabetes have a higher risk of developing Alzheimer later.

Problems associated with Diabetes like obesity, heart disease, high cholesterol or high blood pressure are also risk factors with Alzheimer disease.

Some people with diabetes may go on to develop Alzheimer but many will not. So maintain a healthy lifestyle that promotes cardiovascular health that benefits your brain and be in touch with your doctor.

Q.10. My father has been a vegetarian throughout his life & has now developed Alzheimer Disease. Can dietary deficiencies cause Alzheimer Disease?

Ans : Research in recent years has found that our diets have a profound impact on our brains. Dietary deficiencies are a rare cause of Alzheimer and it is caused by vegetarian food, is not true.

Deficiency of some vitamins like B^{12} or B^{1} (Thiamine), have been implicated as a rare cause of Alzheimer. So people on a vegetarian diet which excludes not only meat but also egg and milk need supplementary vitamin B^{12}.

You can get your father's blood test for vit.-B^{12} done to exclude this possibility after consulting your doctor.

Q.11. If there is no cure for Alzheimer why is early diagnosis a good idea?

Ans : Detecting the disease in its early stage gives you an advantage in many ways. If you suspect that you or a loved one are showing signs of cognitive decline, then early detection and diagnosis are important for many reasons.

- At this point you can still actively participate in your choice of medical care and caregiving.
- You can still make practical decisions about your finances, legal matters and your living situation.
- The cognitive decline may be caused by something treatable such as depression or a vitamin B12 deficiency or hypothyroidism and early diagnosis prevents future decline.
- Medication and other approaches may be used to manage symptoms.
- It alerts doctors and family members to the possibility that the person may need assistance with daily tasks such as cooking and managing medication etc and plan for the future.

- It may reduce falls and other accidents as caregivers are more aware of the danger.

Q.12. What is mild cognitive impairment? How is it different from Alzheimer?

Ans : Mild Cognitive Impairment (MCI) is a condition characterized by memory issues or other thinking problems that are greater than normal for a person's age and education but not serious enough to interfere with a person's ability to function independently . Many but not all people with MCI progress to Alzheimer disease. The kind of problems associated with MCI may also be caused by certain medications, cerebro-vascular diseases and other factors. It is important to talk to your doctor because some of the problem brought by these conditions can be managed or reversed.

Experts can evaluate the extent of cognitive impairment by using neuropsychological tests to measure changes in memory, language and other cognitive abilities. Not everyone with MCI develops Alzheimer.

Q.13. What are the risk factors of Alzheimer disease?

Ans : This is an important current area of research. A great deal still remains to be discovered about the causes of Alzheimer Disease. So it is important to understand risk factors other than genetic ones that may increase your odd of developing Alzheimer Disease.

1. ***A family history*** of Alzheimer raises the doubts that you will get Alzheimer Disease. But

just because a family member has Alzheimer Disease does not mean you will get it.

2. ***Age :*** It is normal to experience a decline in memory and cognitive function as you get older, but not everyone gets Alzheimer Disease simply because of age. No doubt, the number 1 risk factor for Alzheimer Disease is advancing age.
3. ***Head Injury :*** Though scientists have yet to determine a link between head trauma and the development of Alzheimer Disease, but research strongly suggests that head injury does raise the risk for developing this disease. A study at the university of Pennsylvania has found that repetitive head injuries accelerate the onset of Alzheimer Disease by increasing free radical damage and the formation of plaque like deposits of amyloid proteins. Other studies have also found that boxers are more prone to memory problems caused by years of fighting in the ring.
4. ***Cardiovascular disease :*** Most of the people know that having high cholesterol and high blood pressure puts them at risk for conditions like cardiovascular disease and diabetes. But recent research is showing that these same risk factors may also play a role in causing Alzheimer. These conditions can damage blood vessels, which supply oxygen to brain, disrupting important neural circuits that are used to perform cognitive functions. It has also been found that a higher intake of fats and calories over time is associated with a greater risk for Alzheimer Disease as more beta amyloid plaques are found in their brains.

5. ***Strokes :*** Studies suggest that people who have experienced strokes are more likely to develop symptoms of Alzheimer. Since the chance of having a stroke is influenced by blood pressure and smoking, there is at least a possibility that some people may be able to prevent Alzheimer or minimize its impact by watching their blood pressure and quitting smoking.

   Studies also suggest that women are more likely to develop Alzheimer Disease than men. But it is hard to predict that all the risk factors mentioned above lead to Alzheimer Disease. As not everyone who gets Alzheimer Disease is a female, or elderly. And not everyone has a history of cardiovascular disease, stroke or head injury. Scientists all over the world are exploring the influence of depression, certain chemicals, environmental toxins, cigarette smoking, impact of life style, food we eat, lack of exercise. By pinning down specific risk factors that raise your doubts for developing Alzheimer Disease, there is hope that the disease might someday, somehow be preventable.

Q.14. How do the early symptoms of Alzheimer disease differ from ordinary forgetfulness?

Ans : It is not easy to distinguish normal forgetfulness that occur with aging, from the onset of Alzheimer. Many times in early stages a person with Alzheimer may be well aware of the shortcoming in his memory and make efforts to hide them, sometimes successfully for several years until he is placed in a stressful or unfamiliar situation.

Another challenge in detecting Alzheimer is the inconsistency of the symptoms. The person's memory may be better on some days than others. Still through the points given below you can get some help in distinguishing normal forgetfulness that occurs with aging from onset of Alzheimer disease.

AGE RELATED CHANGES

1. Occasionally forgetting names, appointments but recalling them later.
2. Getting confused about day of the week but figuring it out later.
3. Vision changes related to cataract.
4. Sometimes having trouble finding the right words and forgetting which word to use.
5. Misplacing things from time to time but able to retrace them.
6. Make a bad decision once in a while.
7. Not interested in family, work, social obligations sometimes.
8. Develop specific way of doing things, become irritable when a routine is disrupted.
9. Disinterested in learning new things.

SIGNS OF ALZHEIMER DISEASE

1. The frequency of your forgetfulness is increasing. Forgetting dates, events and repeatedly asking for the same information.
2. You cannot keep track of what happened each day.
3. Vision problems leading to difficulty in reading, judging distance and driving.

4. Difficulty having a conversation, repeating phrases or stories in the same conversation, using wrong names.
5. Putting things in unusual places, unable to retrace them, accuse others of stealing.
6. Major changes in judgement, planning and decision making. Paying less attention to grooming and cleanliness.
7. Avoids and withdraws from social work and family leisure activities.
8. Personality becomes confused, suspicious, depressed, fearful, anxious and upset.
9. Having difficulty in learning new things. Also have trouble remembering how to do things which you have done numerous times before, like paying bills, handling money and making choices.

If you notice any of these signs in someone you know or in yourself, don't ignore them. Go to a doctor and get thorough medical evaluation done.

Q.15. My father has Alzheimer. How do I communicate with him?

Ans : As Alzheimer disease progresses, communication becomes very difficult. People with Alzheimer Disease develop problems both in expressing themselves clearly and in understanding what is said to them. There are quite a number of things that you can do to help you and your father to communicate.

- First of all attract your father's attention before you speak to him by gently touching his arm.

- Try to avoid other distractions eg. Tell him that you are switching off T.V. or music system so that you can talk to him.
- Make sure he can see, hear and speak as clearly as possible. Check his hearing aids, dentures and spects to make him comfortable.
- While communicating, try to keep your head and shoulders at the same level as his.
- Try to maintain eye contact when either of you is speaking.
- Try to hold his hand during your conversation.
- Try to be as calm as possible and allow enough time for a response. Do not interrupt.
- Use short sentences and try to talk about only one thing at a time. Speak as clearly as you can.
- If you find him struggling to find a word or communicate a thought, gently try to provide the word he is looking for.
- It would be better to reply to him with short answers like "Yes" or "No" as he may have difficulty comprehending complex sentences.
- Avoid talking to him like a baby.

Q.16. My wife has Alzheimer disease in second stage. She stays all alone during the day as our children are settled abroad. What all can I do to help her?

Ans :

- Hire a part time female caregiver who is trained as per the requirements of your wife. (Hope Ek A.S.H.A can help you).
- Put bold labels in the house specifying the different areas like bathroom, bedroom etc.

- Keep the dark passages of the house illuminated at all hours.
- Play soothing music during the day as studies have proved that music therapy is beneficial in Alzheimer Disease patients.
- The room should be well ventilated.
- Her slippers or other footwears should be comfortable to avoid tripping.
- There should be no loose torn carpet or foot mat especially on the stairs or door ways.
- Furniture with pointed edges or protruding legs should be kept aside.
- Safety regarding cooking gas, electric gadgets etc should be taken care of.
- Label cupboards and drawers with words or pictures that describe their contents like sweater, socks, etc.
- Home should be locked in a way that she doesn't go out alone.
- Stay connected socially and do not hesitate to ask for help from nears and dears. Hope Ek A.S.H.A. is also there to help you.
- Maintain her dignity as she has not lost all the memory.
- Play games like scrabble, ludo, carom to stimulate her neurons. Some simple painting sheets can be given to her to colour.
- Go through old family albums and refresh the memories. Put pictures of close family members on the wall. It is difficult but not impossible.

Q.17. Is Alzheimer disease covered by Medical Insurance in our country?

Ans : Currently Insurance companies do not cover Alzheimer disease medication and care. Rather in our country the insurance for senior citizens does not cover domiciliary care and Alzheimer Disease needs care at home. For latest developments please contact the insurance companies.

Q.18. Where should I go for help as I suspect I may have Alzheimer disease?

Ans : First, visit your regular Family Physician. The physician will probably do a number of tests to determine the probability of Alzheimer Disease. Specialists such as Neurologists, Gerontologists and Psychiatrists may also be involved in the evaluation process.

Q.19. What information should I take on my first visit to the doctor in case I suspect I may have Alzheimer?

Ans : When you first visit the doctor take all your medical records like a list of over the counter and prescribed medicines you are currently taking. In case you don't know the names of the drugs, take the wrapper with you.

- Also make a list of current medical problems, list of symptoms, behavioural problems and any difficulties you are facing in carrying out routine activities like dressing, bathing, driving, paying bills etc. that concern you.
- Also make a list of things you generally forget.

Q.20. Is there a connection between Alzheimer and Aluminium or other metals?

Ans : Metals have been implicated in neuro-degenerative diseases, although it is unlikely that any metal is the sole cause. This is a controversial issue. Aluminium has never been proven to be a direct cause of Alzheimer and evidence shows that Alzheimer disease is caused not by one, but a combination of factors. However, a large study of the brain of people who had died from Alzheimer Disease did not find higher than normal levels of aluminium.

Q.21. Why it is that my wife, who has Alzheimer is able to remember things from years ago but can't remember what happened half an hour ago?

Ans : There are several linked processes involved in memory. First an experience is perceived, it is then placed in a short term memory store and retained for a brief time. If the experience recurs or is likely to be important, it goes into a long term memory store. Finally for a memory to be recaptured it must be recalled from a memory store.

People with Alzheimer gradually lose the ability to enter new information into their memory. They also have difficulty in recalling previously stored memories. Memory for recent events is affected first. Typically, memories that are well encoded are those your wife will remember best as she had lots of practice recalling those memories over the years.

Q.22. What is the cost of the treatment of Alzheimer disease?

Ans : The cost of the treatment of Alzheimer disease is exorbitant. Elderly people afflicted with Alzheimer Disease have various other ailments like diabetes, hypertension, cataract, impaired hearing etc. The monthly budget for medicines is anywhere between Rs. 10,000 to 15,000. The cost of professional caregiver varies from patient to patient and on an average it is 15,000 to 20,000 per month or may be more according to the training and experience of the caregiver.

Q.23. How long does Alzheimer disease last on an average?

Ans : On an average patients with Alzheimer disease live for 4 to 10 years after diagnosis. However this terminal disease can last for as long as 20 years.

Q.24. My wife is becoming forgetful day by day and she is only 50. Can there be a possibility of her having Alzheimer disease?

Ans : Though Alzheimer disease commonly affects people above the age of 60, but it has been seen in younger individuals also. An extensive neurological and Neuropsychological analysis must be done to rule out Alzheimer Disease.

Q.25. My father-in-law clearly has a problem with his memory. He is very active and unaware that he has a problem. He is 70 years old and is still working. How can I support him?

Ans : It is important to help him remain independent for as long as possible by being flexible and patient with him.

- ***Encourage him to remember what he can without making him feel pressured :*** using frequent reminders and doing things with him rather than for him. Rather than asking him to recognise his nephew say "This is your nephew Rajiv".
- ***Store memories externally :*** For instance display photos of people very close to him, create a scrap book with his photos and also make audio or video recordings of his life stories.
- Talk about his family history, traditions, important events, his favourite books and hobbies.
- Sometimes he may seem to be living in the past. In such a case, those around him should try to relate to what he is remembering or feeling rather than contradicting him.
- Help him remember new information by :
  - * Keeping information simple
  - * Repeating it frequently.
  - * Breaking new activities into simple steps.
- Avoid unnecessary stress
  - * Give him support
  - * Help him concentrate on one thing at a time.
  - * Try to make sure that there are no distractions.
  - * Provide him verbal clues.
  - * Put a regular routine in place and remind him about meal times, appointments.

- Label cupboards and drawers with words and pictures that describe their contents such as shoes, socks, shirts etc. Also label in bold letters bathroom, drawing room and kitchen.
- Even if outwardly he looks active and you feel he can handle, be careful with electrical appliances. Leave written reminders to unplug iron, turn off the gas. Buy appliances with automatic shut off features.
- Keep an ID card in his purse or pocket with his name and phone number of someone who can be called in case he forgets the way back home.
- Encourage him to play Sudoku, cross word puzzles and other memory games for mental stimulation.
- Try to persuade your father-in-law to see his doctor. If that is not possible, because he insists that he sees no reason to go, then it might be useful to talk about his condition to his doctor yourself.

It is important to focus on what your father in law can do rather than what he cannot do.

Q.26. My husband is a passive smoker and an alcoholic. Does drinking too much alcohol or passive smoking cause Dementia?

Ans : People who drink too much alcohol do seem to be at a risk of developing problems with their memory. Some have a specific problem of loss of short term memory, others develop a wider range of problems that resemble Alzheimer disease. Alcohol can damage their brain directly as a neurotoxin or it can damage it indirectly by causing malnutrition primarily the loss of thiamine (vitamin B^1). Alcohol related dementia is under-diagnosed, so drinking moderate amount of alcohol is probably safe.

Smoking is not thought to be a direct cause of dementia but it can contribute to atherosclerosis (narrowing of arteries), which often leads to a stroke. One form of dementia called vascular dementia is caused by strokes which causes brain damage by cutting off blood supply to areas of the brain. Better don't smoke as it is bad for the heart, lungs and vascular system.

Q.27. My mother-in-law has Alzheimer. There are days when she doesn't sleep and then she sleeps the whole day. Is it normal. How can I help her?

Ans : Some people with Alzheimer disease sleep so much while others have difficulty getting enough sleep. Alzheimer Disease causes a loss of brain cells and interferes with communication between many of the remaining cells. The control centre for sleep is located in the middle of the brain and Alzheimer Disease affects this control centre which leads to many kinds of problems for the patients.

There are conditions in which involuntary movements interfere with sleep like periodic limb movement and restless leg syndrome or pain in a body part. Other common conditions that disrupt sleep include night mares, sleep apnea and an abnormal breathing pattern. Depression in Alzheimer Disease patients may further worsen sleep pattern.

- Get her evaluated by her physician to rule out other medical issues, a psychiatric problem or a medication that is disturbing sleep.
- Establish regular meal times.
- Avoid excessive evening fluid intake before making her sleep.
- Establish a comfortable, secure sleep environment.
- Try to indulge her in various activities in the day time to avoid day time naps. In case she sleeps during the day, wake her up. Encourage a friend or a relative to visit her during the day. Give her painting sheet with a figure drawn on it to colour with crayons, show her family album. Light music of her choice can also be played.
- Sleep inducing medication increases the risk for fall and fractures, increases confusion and decline the ability to care for oneself so try to discontinue these medicines after a regular sleep pattern has been established.

It is difficult to keep Alzheimer patients occupied but it is worth making the effort.

Q.28. Can Alzheimer disease occur in younger adults?

Ans : Yes, though less frequently. The disease can occur in people in their 30^s - 40^s - 50^s. However, most people diagnosed with Alzheimer Disease are older than 60. The early onset of the disease that strike younger people accounts for less than 10 percent of all reported cases. Alzheimer Disease in early age is usually gene linked.

Q.29. My mother, who has Alzheimer disease, seems to be having hallucinations. She talks to imaginary persons and seems to see things that don't exist. Sometimes she becomes very frightened and upset. How should I respond?

Ans : Hallucinations – in which people see, hear or sense the presence of someone or something that is not there, is a common symptom in Alzheimer Disease. Hallucinations seem very real to Alzheimer Disease patients so they feel frightened and upset.

When your mother gets upset by a hallucination, offer her reassurance and physical comfort by giving her a hug or holding her hand. Don't argue with her on this, neither pretend that the content of her hallucination is real. Try to distract her patiently, by giving her a drink.

Hallucinations are sometimes associated with poor vision so get her eyes checked. Keep her room well lit as this will make your mother less likely to misinterpret what she is seeing. Talk to her doctor about this as there might be some medicine causing hallucination as a side effect.

Q.30. How is Alzheimer disease usually diagnosed?

Ans : There is no single comprehensive diagnostic test for Alzheimer disease. Diagnosis is usually made on the basis of a patients symptoms and mental abilities.

Unlike many diseases which can be diagnosed by a marker in the blood or an X-Ray, Alzheimer cannot be fully confirmed until autopsy, when the plaques and tangles can be seen in the brain.

Having trouble following instructions, losing one's orientation, display of poor judgement and having difficulty managing money, shopping or driving are all possible symptoms of Alzheimer disease. When a person is experiencing such declines, visit the doctor for the medical examination which usually includes.

a) ***Patient History*** which includes observations by members of the family, family history of dementia, mental well being which includes assessing for depression and current health status. In case one has a family history of Alzheimer Disease, Genetic test might be done.

b) ***Physical examination :*** The doctor will take your blood pressure, pulse, temperature and measure your height and weight.

c) ***Blood and urine tests*** will be done to reveal infections, liver or kidney problems, diabetes and anemia. Deficiency of vitamin B12, metabolic imbalances in thyroid, can also cause symptoms of dementia.

d) ***Mental status :*** With the help of Mini-Mental state exam, the doctor will come to know about ones mental abilities namely memory, language and organisational skills. This test includes questions regarding the person's whereabouts and he is asked to perform simple tasks to evaluate his ability to remember, understand and communicate. A low score alone does not indicate that the person has Alzheimer but simply suggests he might have.

e) ***Neurological exam :*** To get an idea of how well your brain and nerves are functioning some neurological tests are done. These exams may help determine which part of the brain is affected.

f) ***MRI :*** Modern science has made it possible now to view the brain through different imaging technologies. In people with Alzheimer Disease, shrinkage in some areas of the brain may be detected through these techniques.

- ***CT scan*** also called computerized Axial tomography or CAT scan. CT scans are useful for diagnosing strokes due to haemorrhage.
- ***Positron Emission Tomography (PET) :*** A PET scan helps reveal which parts of the brain is working hardest during particular mental activities. In a person who has Alzheimer, a PET scan typically shows less brain activity than that which occur in a healthy person.
- ***SPECTS*** or Single photon emission computed tomography is another scan that looks at blood flow through the brain rather than the structure of brain. Research suggests that the information provided by a SPECT may help in confirming the diagnosis of dementia in some cases.

The doctors rely on the results of all these different evaluations to determine whether one has Alzheimer Disease, some another form of dementia or it is Mild Cognitive Impairment (MCI).

Scientists have recently developed a number of new bio markers and brain scanning techniques that may help to improve diagnosis of Alzheimer Disease.

Q.31. My mother who lives with us, has been diagnosed with Alzheimer disease. How can I make my teen aged children help me in care giving?

Ans : First of all educate your children about the disease and encourage them to ask questions about it.

Understand their feelings and emotions because after knowing about it they might feel worried, fearful and embarrassed. They might display behavioural changes like doing poorly in school, not inviting friends to the house any more, spending more time away from home or complaining of vague physical discomforts such as headches or stomach aches.

- This is a difficult time for all of you. The best way of helping your children to cope with it is to give them plenty of explanations, reassurance, hugs and love.
- When you feel they are comfortable offer them tips on how to relate to their grandmother like speaking more slowly, providing her frequent reminders and accepting that she can no longer do what she used to do.
- Encourage them to be with her in activities like watching a movie, seeing old albums together and discussing, listening to music, reading together, taking a walk, making her do some colouring with crayons, making scrap book of past events, play games according to her condition, string beads, fold laundry, sing songs, put a puzzle together, toss a ball etc.
- Appreciate their efforts and help them see how their involvement benefits their grandmother.

It is a well know fact that children can reach demented people at a deeper emotional level that adults often cannot. Faces may remain blank when an adult enters the room, but when a child walk in, those stares may turn into smiles for Alzheimer Disease patients in the later stages of the disease.

Q.32. I want my wife, who has Alzheimer to carry on dressing herself for as long as possible. However she finds it increasingly difficult. Please suggest how can I make dressing easier for her?

Ans :

- Keep encouraging your wife to dress herself, as this will help her to retain sense of independence and self-esteem.
- Make sure that the room is warm and she is given enough time to dress herself. Make sure that blinds and curtains are closed and that no one walks in to disturb her while dressing.
- She will be able to manage better if you lay her clothes in the order she needs to put them on, starting with underwear. In later stages you will probably need to hand her clothes one at a time and give instructions or demonstrate as to how to put them on.
- Get some easy to wear clothes for her. Neck openings should be of a good size. Sleeves should not be tight. Clothes should have velcro fastenings or elasticated openings as it will be simpler than clothes fastened with buttons. Front fastening will be better.
- In case your wife has been used to wearing more traditional clothes in the past, she may not like

to change. Do try to involve her in choosing what she is going to wear each day. Too many options may be confusing so make suggestions one at a time. Best will be to put the things she wears more frequently somewhere accessible. This will make it easier for her to choose.

- Get well fitted slip-on shoes for her with velcro fastenings, as it will ensure good grip while walking and reduce chances of falling.

Q.33. My wife who has Alzheimer wants to wear same clothes everyday. She used to be very smart and active but now she often looks untidy. She gets so upset if I try to explain things to her. What should I do?

Ans : Your wife probably no longer recognises and understands the need to change her clothes nor she knows which ones are clean and which needs washing. Only possible way that might work is to encourage her to have a bath and then take this opportunity to remove the clothes that need washing and to lay out a clean set for her. By doing this you will not hurt her feelings as she will probably not notice what you have done. If she likes to wear one type of dress buy several just like it and if she insists on wearing same shirt everyday, just wash it when she is asleep so that it is ready to wear next day.

Keep her favourite tooth paste, make up or cologne to use. If possible call her beautician at home someday for grooming, pedicuring and manicuring her. This can boost her self esteem.

Q.34. My mother-in-law who has Alzheimer, is reluctant to take bath and hates to wash her face. How to take her for bath?

Ans : To convince an Alzheimer patient to bathe often require tact and diplomacy. They become resistant to bathing because they don't remember what bathing is for. If reminders of the need to bath are no longer effective, then establishing a regular time for bathing may help. If this motivation also slips, try to tell her that she has to go out or some guests are coming home for which she needs to be well groomed.

- Never criticize her about her cleanliness. When she is freshly bathed and dressed praise her.
- While helping her to take bath wrap her completely with a big towel for privacy and warmth.
- Your mother-in-law no longer understands the need to wash her face. May be she finds it undignified to have someone else wash her face. Don't panic on this and wipe her face with soft wet towel or flannel cloth.
- To make bathing activity safer use non slip mats in the bathroom floor and at the entrance.
- Shampoo, soap, toothbrush etc should be ready before hand.
- Check the water temperature first and then make her sit on a comfortable water proof, chair.
- Never leave her alone in the bathroom.
- Use products made of unbreakable materials and keep sharp objects like tweezer, scissors out of reach.

- You may need to remove locks and bolts from the bathroom door for her safety.
- Give her choices. Ask "would you like to take a bath or a shower? or Do you prefer a bath now or in 15 minutes. In case she resists bathing, distract her or try again later.
- If possible a familiar person of same sex should help her in the bathroom.
- Be aware that your mother may perceive bathing to be threatening. So be prepared as she might become agitated. For this you can play soothing music or sing for her to distract her.
- Remove or cover the mirror if any as she might believe there is a stranger in the bathroom.
- Guide her in each step by politely saying "Sit down mom" "Here is the soap", "Wash your hands".
- Be Flexible. Do not worry about the frequency of bathing. Sometimes sponge bath with a wet soft cloth can be given as an alternative.

Q.35. My husband has been diagnosed with Alzheimer disease. He has begun to wet the bed (Incontinence) what should I do?

Ans : First of all speak to his physician to rule out the causes for bed wetting like diabetes, urinary tract infection, urinary tract stone, neurological disorders, prostate enlargement, acute anxiety, prostate or bladder cancer or any other reason.

If no treatable cause for the incontinence is found then there are a number of practical steps that you can take to reduce the problem.

- Try to limit intake of fluids in the late evening before bed time.
- Also decrease the amount of caffeinated beverages. eg. Tea, coffee.
- Label bathroom doors with words and toilet pictures.
- Make sure clothes which he is wearing are easy to remove with velcro fastenings or elastic waists.
- Order for a waterproof mattress for him.
- Give reminders to go to the toilet eg. every two hours in the morning , upon getting out of bed, at bed time or before going out.
- You may find it helpful to wake him once or twice during the night for a toilet visit. Give him simple instructions.
- In case he is frequently incontinent and this does not change, after consulting with a physician and implementing above suggestions you can purchase adult diapers for him.
- You can also use a commode or a urinal in the bathroom.
- See if the mirrors in the bathroom are a problem as he may feel as if someone else is there in the room.
- Leave the door open to the bathroom when not in use. Remove locks.
- Leave him alone if he prefers, but stay nearby. You can tell him that you are just outside the door if he needs anything.

Incontinence will mean a lot more work for the caregiver. It is important not to get angry and bitter.

Remember this is happening due to disease, and is not your husband's fault. He may be as distressed as you. It is important to understand that you are doing the best you can.

Q.36. My mother-in-law, with Alzheimer, refuses to eat anything at all. She has a small appetite. How can I persuade her to eat?

Ans : Providing adequate food and fluids during various stages of Alzheimer can be challenging for the family and caregiver. Not eating enough can lead to weight loss and other problems including vulnerability to infection, reduced muscle strength and fatigue. So a healthy balanced diet is important.

First of all we need to find the reasons for poor appetite or refusal to eat.

- She might be depressed or has forgotten how to chew or swallow.
- She may have problems communicating that she is hungry or she doesn't like the food being served to her.
- There may be some problem in teeth or her dentures making chewing or swallowing difficult.
- There might be a problem with concentration or difficulties with coordination like getting food from plate to her mouth or she may not open her mouth and need reminders.
- Change in medication sometimes result in appetite changes.
- Lack of any physical activity can be another reason.

- Constipation can result a person feeling bloated or nauseous, thereby decreasing the appetite.
- Consult your doctor for medical issues.
- There are lots of ways to stimulate appetite and interest in food and drink.
- Try to make a calm, relaxed, unhurried routine. Soft music may help. Finger food can be given to her in case she is not comfortable with spoon. Also make small portions for her.
- Reduce distractions in eating area. In case she is agitated or distressed, do not put pressure on her to eat or drink. Wait until she is calm and less anxious.
- Do not criticize if she makes a mess. Encouraging her to continue to feed herself on her own for as long as possible is important for her sense of independence and self esteem.
- If she is very forgetful, you may need to prompt her to take another mouthful or to chew or swallow it, pick up spoon etc.
- You have a better idea about her likes and dislikes so the aroma of cooking she like can stimulate her appetite. Be flexible as her tastes might change frequently as Alzheimer patient can show greater problems with their sense of smell especially with odour memory.
- Try to give her regular snacks or small meals rather than set meals.
- If she has a preference for sweet food, fruits may be a healthier option.
- The most important is that even if she does not want to eat, you should try to make sure

that she drinks enough liquids to avoid dehydration.

- Make eye contact while she is eating and smile before she starts eating.
- Walking or participating in other light activities can help stimulate appetite.
- Talk to the doctor in case you feel she is suffering from some treatable disorder such as heartburn, constipation, nausea or sore mouth that may be affecting her appetite. Discuss with him her lack of interest in eating as he may need to change any medicine.

Q.37. My husband who has Alzheimer disease sometimes forgets that he has just had a meal. He then complains about being hungry and repeats that I never give her anything to eat. What should I do?

Ans : It is quite common with Alzheimer patients to forget that they have had a meal. Your husband no longer knows when he has had enough to eat probably because the disease has affected the so called satiety centre in the brain. The satiety centre's normal function is to let people know when they have had enough to eat and when to stop eating food in general.

- There can be a medical reason like diabeties or the medication he is on might be showing some side effects. So talk to his doctor.
- If your husband asks for another meal when he has just eaten, the best plan is to try to distract him with some activity like puzzle, card games, colouring, walking or increased social contacts etc to keep his focus off food.

- Try to offer non-fattening snacks or fruit like berries, apple or some raw carrot etc. to eat while he is waiting. This will be filling also and won't cause weight gain. This might not always work but don't give more food till next meal.

Q.38. My father has recently been diagnosed with Alzheimer disease. He still likes to go for short walks on his own. I am worried that he might get lost. What precautions can I take?

Ans : Wandering is quite common in people with Alzheimer. As a caregiver you need to know how to limit wandering and prevent him from being lost. This will help keep him safe and give you greater peace of mind.

You should prepare yourself for the likely decline in your father's memory as he may get lost?

- Make sure your father carries some kind of ID card with his name, address and phone number on it. In case he refuses to carry an ID card, you could have a bracelet tag engraved at a local jeweller.
- Let neighbours, local shopkeepers and local police know that your father has Alzheimer disease and tends to wander out.
- Keep photographs or video recording of your father to help police, if he ever gets lost.
- Keep doors locked.
- You can also get a system, that chimes when the doors open, installed in the house.
- If possible you can appoint a helper who can go with him when he goes out.

Q.39. How can I persuade my husband who has been diagnosed with Alzheimer disease, that he should not drive his car now as it is not safe?

Ans : Research suggest that many people with Alzheimer continue to drive after the onset of the illness, but in an unsafe fashion. The main problem is that as the disease progress, the ability to drive deteriorates. It is important that anyone who has become an unsafe driver should not be allowed to continue driving, however upsetting this may be.

In case you see the following signs in your husband's driving, it is sure that he has become unsafe on the road.

- Forgetting how to locate familiar places.
- Failing to observe traffic signals.
- Making slow or poor decisions.
- Driving in an inappropriate speed.
- Becoming angry and confused while driving.

If you see these behaviours in him, you should suggest him to stop driving. If he is reluctant you will have to take more assertive measures to get him to stop, which might not be easy.

- Begin with a frank discussion about his driving abilities.
- Avoid criticizing his driving, but do gently point out that some of his skills are not what they used to be.
- You might also start getting him accustomed to not driving by offering to call a part time driver or arrange for other means of transport. After sometime he might come to enjoy and even prefer, going with the driver.

- In case he still insists on driving, control access to the car keys. Put them in places where he won't look.
- Ask a doctor to write a "do not drive" prescription so that he is less angry with you.

If you sense that his skills have become diminished please take action immediately.

Q.40. My father-in-law who has Alzheimer disease keeps on asking me the same question and it drives me crazy. I get irritated and yell at him. Then he is upset and I feel sorry for yelling. How can I learn to have more patience?

Ans : Repetitive behaviours and verbalization result due to the inability of the individual to retain information. Alzheimer Disease patients do not recall that they have just asked that question nor do they recall the answer due to short term memory loss.

- The Memory Loss gives the person a general feeling of insecurity. Repetitive behaviours are created by stress, anxiety and fear that are produced due to this loss e.g. presence of the caregiver can provide a feeling of security and being separated can cause anxiety and agitation causing repeated questions like where are they? When are they returning? etc.
- The inability to judge time can create unnecessary anxiety or confusion when the person thinks that the caregiver has been out for a long time when actually it could be only a few minutes since they left.
- Due to memory loss your father-in-law is losing control of his life. By asking repetitive questions

and making repetitive statements he is asserting his presence, demanding attention, expressing anger and frustration.

- Behaviour of your father-in-law can be a source of frustration and stress for you as a caregiver but you need to be patient and follow these **simple tips.**
- Try to make him feel more secure.
- Sometimes, instead of answering the question again and again, tell him that everything is fine and you are taking care.
- You can also write the answer on a paper and if he asks you the same question you can direct him to the written answer instead of answering again.
- If he continues to ask one particular question despite answering & reassurances, try to distract him by changing the subject or hugging him. Pleasant diversions like taking a walk, listening to soothing music, singing, looking at old albums may help him enjoy the activities and that brings relief from repetitive actions and verbalization.
- Redirection changes the focus from anxious behaviour to something pleasant; such as sorting activity like giving laundry basket filled with socks and ask your father-in-law to match the socks and fold them – sorting nuts, whole pulses, beads etc can help in focussing on a task and feel useful again.
- Do not say “I’ve told you the answer many times” This response will increase anger, agitation and perhaps even escalate the behaviour to catastrophic reaction. They can not comprehend your anger but can feel it.

- Do not tell him about any upcoming event in advance as this will create anxiety that he won't be able to identify. Planned visits, appointments or events should not be revealed to him until it is time to get ready as learning of future task is one of the major causes of repetitive questioning and behaviour.

Q.41. My father is 60 years old, a professor by profession. I feel he is heading towards early stages of Alzheimer. What do I do about his job?

Ans : Whether someone with Alzheimer Disease can still hold a job during early stages of the disease depends greatly on the type of job he holds. As he has a job that requires a lot of concentration, memory and communication skills he might have to stop working as soon as his colleagues notice the changes in him. He can continue doing things that may be possible for a while but he will have to stop working before he is ready to retire.

- To figure out what needs to be done is to start talking about his problem to his employer. He might offer to switch him to a less demanding position, cutting his working hours or give him responsibilities that are less taxing.
- Also talk to your family physician and find out how long he thinks your father can continue working.
- To help him do his job better use reminders memos and a calendar.
- Look into early retirement options.
- When he stops working, find an activity he will enjoy & keep him busy.

Q.42. My husband and I have always gone to a temple on Tuesdays and he has been very particular about all religious ceremonies. Now that he has Alzheimer disease, he does not understand much but I feel he still enjoys this visit. I worry about people around in the temple as he makes disturbing sounds or stares at them. How can I try to meet the spiritual needs of my husband?

Ans : Some people with Alzheimer disease might enjoy the familiar routine of a religious service. For others, a large group of people might be anxiety provoking, so be sure to observe and then respond to your husband's reaction.

The ritual of familiar religious ceremonies can be very helpful and calming for a person with Alzheimer Disease, and they should be given the opportunity to attend their place of worship for as long as they are able to. Other worshippers around will probably be very tolerant and helpful if you explain the situation to them.

- In case you find it difficult to take your husband to the temple, you can call a Pandit ji to visit him and say prayers for him or with him.
- Document his religious denomination, favourite prayers, inspirational passages and meaningful rituals as this will help you in providing an effective level of spiritual care to your husband.
- Play religious songs and hymns from his era for comfort and spiritual well being as he will have memories of the songs he sang as a child or at a younger age.
- Encourage his friends to visit and sing familiar religious Bhajans with him in a group.

- Show him pictures of God figures he has been worshipping in the prayer place made at home.
- In case he has been accustomed to hearing religious programmes on T.V. or music system, facilitate access to this service but less on T.V.
- Music can have many beneficial effects ranging from reducing feelings of physical pain to enhancing the memory. So you can play some religious music and prayers he has been reciting.
- People with Alzheimer Disease generally feel calmed, encouraged and uplifted by prayers. Spare some time for doing prayers together. This can also be done in a group for him in case he is comfortable.
- Take out time to read passages from holy books he has been reading. Recite his favourite verses or prayers, he might have memorized when he was fine.

Reognise and believe that every patient has an intact soul. Be authentic in your expression of love, kindness and concern. No matter how tangled or difficult the communication might be, it is possible with patience and determination.

Q.43. My husband who has Alzheimer follow me from room to room. Even when I go to the toilet he keeps on knocking on the door to make sure I'm still there. I am suffocated sometimes and feel I have no space for myself. I feel like a prisoner emotionally, mentally and physically. It is true that it's me who needs to change, but it gets me down. Please help?

Ans : Alzheimer disease patients generally feel scared and insecure so they follow their caregivers. Your husband probably thinks you are not going to return and this makes him feel very unhappy. You are in a way a comfort blanket for his insecurity. You are not being mean as it is a hard work and this behaviour is exhausting as well as draining.

- Whenever you leave the room it is important to try to reassure your husband that you will be coming back in a few minutes.
- To get some space and time for yourself, you can ask your children, a friend or a neighbour to sit with him for some time. This will help you feel more relaxed and may make it easier to cope with your husband's clinging behaviour when you return.
- Join a caregiver support group to get some help. In these groups Alzheimer Disease caregivers share their experiences and give each other tips and support.
- You can also hire a trained male attendant for him who helps him in daily activities and your husband might start feeling connected to him.
- If you feel you are going to lose your temper, try to go to another room, take a deep breath, listen to your favourite music and relax.
- Take care of your health too.
- Take help from other members of the family, good friends or neighbours like making a meal, getting grocery item from the market or taking your husband for a walk so that you get some rest.

The change will come only when he is not mobile anymore, providing with a new set of challenges. So you need to show patience.

Q.44. My mother who has Alzheimer disease is staying with me. I don't mind caring for her, but I feel very bitter about my brother and his wife who never come to visit her and refuse to take her home, that belongs to my mother. I have given up my job, so we are on single income and my brother doesn't contribute anything financially. They hardly inquire about her well-being. What can I do about this as I feel exhausted physically and emotionally?

Ans : Alzheimer disease doesn't just affect the person who has it but it affects the whole family and many relationships too. Sometimes one member of the family like you, shoulder the whole burden, while others like your brother, keep away and refuse to share the responsibility. This often leads to bitterness and family feuds.

Family disagreements are infinitely complex but two main reasons of disputes about their parents care are :- Injustice and inheritance. You know better if these reasons are affecting you in any way.

Injustice : As you are taking care of your mother the sense of unfairness is causing feeling of resentment in you.

Inheritance : Many siblings clash over parent's finances. A sibling who provides most of a parent's care may feel entitled to a greater share of an inheritance or siblings who are more distant or not involved in caring may believe that the caregiving sibling is over spending on parents care.

There are no easy answers to settle the differences between brothers and sisters, still it is better to communicate with your brother.

There should be a frank and open discussion about your mother's needs. Each siblings role and obligations should be established and future plans to be made.

In case you find it difficult to communicate with your brother, it would be better to take the help of a family senior or a counsellor who can act as a mediator to bridge the difference between you two.

Ultimately, the one person we can change is ourselves. While advocating for what's best for our parents, it is wise to let go of anger or resentment towards a sibling who has been unhelpful or hurtful for your peace. Join a support group for help and guidance. You may feel less stressed and bitter about your brother after talking to people in this group with similar experiences.

Q.45. My wife has had Alzheimer disease for ten years. My children are settled abroad. I am so exhausted physically and mentally that I want to admit her in a nursing home for some time. I feel so guilty for giving up caring. Please help me?

Ans : The decision to move someone you love in a nursing home is one of the most difficult and painful decisions for a caregiver. If you feel guilty for admitting your wife in a nursing home ask yourself "If I am exhausted to that extent that I feel depressed what good will I do to my wife?"

Seeking support and maintaining your own health is key to managing your role as a caregiver and does not make you a failure. You have cared for her for quite a long time and surely you always felt you would be able to continue to care for her indefinitely.

Caring for Alzheimer Disease patient becomes a 24 hours occupation and it is not normal for anyone to continue to care without break.

You probably feel guilty because in a nursing home the care is not going to be so personal and you may feel you have let your wife down. You should also realise that nothing you did or did not do could have prevented the disease. All you can do is to ensure that your wife is comfortable and safe.

Make sure that the nursing home in which you have to admit your wife is well equipped for Alzheimer Disease patients.

- The nurses are qualified and trained to handle Alzheimer Disease patients.
- The distance to reach the nursing home from your house is not much so that you can be with her once or twice a day to make her feel secure and happy.
- Check that the nursing home is registered with and inspected by the government approved health departments.
- The environment in the nursing home is friendly, welcoming, homely and it is clean.
- There is access for wheel chair and arrangements for activities for Alzheimer Disease patients.
- Also taste the food they are providing to be sure that it is nutritious and hygiene is maintained.

Spend some time with yourself so that you become healthy and relaxed to look after her again when she is back home.

Unfortunately in India there are not many nursing homes for adult patients with Alzheimer Disease.

Q.46. How can a Day Care Centre help me in caring for my mother who has Alzheimer disease. I feel there is a dire need for a good Day Care Centre in India. I also need to know about a support group for Alzheimer Disease patients?

Ans : Yes there is a dire need for good Day Care Centres in India. We at Hope Ek A.S.H.A. (a voluntary Research organisation Dedicated to care of Alzheimer Disease patients and their caregivers) are trying hard for government support to establish Day care centre for Alzheimer Disease patients. This scarcity is due to lack of awareness on public level as well as on government level. The importance of Day Care Centres is not yet prioritized in India. We need to approach to social welfare departments for this as the need is going to increase day by day. Nearly 4 million people are living with Alzheimer Disease and other dementias in India and this is likely to double up by 2030. We hope to get success soon.

We at Hope Ek A.S.H.A. have formed a Support Group to help Alzheimer patients and their families to cope with the disease.

- Our Support Group provides a forum for exchanging information about the disease and ways to cope with it. Whether it is about new research, strategies for dealing with difficult behaviours or ways to manage new challenges, Caregivers learn from one another.
- We have renowned doctors, clinical psychologists & social workers and many caregivers to share their experiences.
- Our support group also provides a safe environment where you can verbalize your thoughts

and emotions among others who share similar problem and can understand your plight better.

- The greatest benefit of a support group is that it makes you feel secure with the thought of having friends who share common experiences. As a caregiver of Alzheimer disease you might be having difficulty relating to relatives and old friends resulting in isolation. With the help of this support group you may enjoy the new friendships and feel emotionally strong.
- To know more about Hope Ek A.S.H.A go to our website www.hopeekasha.org.

Q.47. What is Respite Care and how can I get it as I feel exhausted sometimes while caring for my husband, who has Alzheimer disease?

Ans : Caregiving is a demanding job which makes carer exhausted physically as well as mentally.

Respite care provides short term breaks that can relieve stress, restore energy and promote balance in caregiver's life. Whether it is a short trip to super market, a chance to get a hair cut or simply a brief visit to the mall or just being with yourself, all this may provide the carer a chance to recharge and rejuvenate.

Respite care can be provided at home or through community organizations.

In Home :

- Members of the family, friends and close relatives may be able to give you short break when you are exhausted. For this you will have to keep everyone in the family upto date on the patients needs and conditions. Be open to their view points and be willing to try new strategies suggested by them.

- You can also arrange for a trained aide on payment basis who can provide you different services depending on your need. Services might include supervision, recreational activities, medical assistance, exercise, housekeeping, meal preparation, shopping or grooming. But make sure to find out about his/her prior experiences and training before fixing up.

Out of Home respite care programs :

(a) Day Care Centre/Respite Care Centre.

Caregivers can leave the Alzheimer Disease patients in day care centres for a few hours.

(b) Private nursing homes also sometimes offer respite care if they have enough rooms. You can leave your husband there for a few days.

People with Alzheimer disease may find it difficult to settle into respite care. If you sense resistance, tell your husband that the aide is a friend who is helping around the house. Arrange to stick around the first few visits until your husband is more comfortable with the aide. If the patients is going to a Day Care Centre you might say that he is going there to work as a volunteer or say it is a social club as this might make the patient willing to go along.

You can also contact us for our Support Group at www.hopeekasha.org that provides members with a forum for exchanging information about Alzheimer that will help you in many ways.

Q.48. Since my husband, who was a professor in Delhi University has been diagnosed with Alzheimer disease most of our friends and relatives have

stopped visiting us. How can I persuade them that Alzheimer Disease, is not infectious and that we need their support at this hour?

Ans : We have different type of friends and it is an old belief that in times of trouble you find out who are your real friends. Don't get disheartened as your friends and relatives are behaving in this manner because of lack of awareness. This doesn't mean they have stopped liking or caring for you. It is just that they don't know how to react to the changes in your lives.

Of course, not everyone may respond to you in the way you hope. Some friends may be terrified after hearing about your husband's Alzheimer Disease and may begin to distance themselves from you. Others on the other hand may offer emotional support and practical assistance. So try speaking directly to the people who have been closest to you and your husband. Let them know that you and your husband need company. If they are real friends then they will support you. Talk it over to your good friends on phone.

Join a carer's support group where you will make new friends who will support you in many ways. You may find that the support group members have become a great source of comfort and encouragement for you. You can verbalize your thoughts and emotions among others who share similar circumstances and can understand your difficulties. Through this group you might come to know about latest caregiving skills and about trained volunteers willing to talk and assist you.

Q.49. How should I take control of my husband's finances who is in the early stages of Alzheimer and is now unable to manage his money safely?

Ans : Increasing trouble with managing money can be an early sign of Alzheimer disease and can quickly drain away personal or family resources. Alzheimer Disease patients have problems in more complicated tasks such as maintaining cheque books and bank statements, preparing tax returns or making wise investment decisions, paying bill etc.

- As your husband is in the early stages of Alzheimer Disease, he may be able to help you plan the family finances, explain his wishes, help you understand bank accounts and bill payment systems. So try to discuss this financial management issue with him with respect and understanding.
- Explain to him politely that it is important for you to learn about finances with his help.
- Find out where he has kept his locker keys and important documents such as the papers of your house, tax return, will or power of attorney if any, bank accounts, monthly bills to be paid, any documents regarding mortgage, his pension papers, insurance details or any other investment done.
- A major concern is to guard him against any fraud. Both strangers and people known to him may take advantage. His credit card can be misused.
- In case your husband resists and feels possessive about his financial affairs give him small amounts in cash or in some cases voided cheques in his hand. Have the credit limit minimised on credit cards or have credit cards cancelled.

For this it may be wise to speak to the bank officials so that they can alert you if your husband takes out more money than he should need. Also talk to the local shopkeepers and make arrangements with them to pay for goods in case your husband refuses to do so.

In case he is able to grant you a power of attorney, you should take steps to arrange this immediately. If he is not capable to grant you this then speak to your Financial Advisor and start the process to become his receiver so that you are able to take over his bank accounts, pay bills and receive income on his behalf.

Q.50. As a caregiver of Alzheimer disease patient I feel stressed, lonely and exhausted all the time. Please help me?

Ans : Caring for someone with Alzheimer disease can be a long, stressful and intensely emotional journey. The burden of caregiving can put you at increased risk of experiencing depression and stress. You might feel sad, anxious, lonely and exhausted at times. Caregivers' stress can be particularly damaging, since it is typically a longterm challenge. You may face years of caregiving responsibilities with no hope that the Alzheimer Disease patient will get better.

When caregiver stress puts your own health at risk, it affects your ability to provide care. The key point is that caregivers need care too. Managing the stress levels in your life is very important.

- ***Learn how to manage stress :*** Meditation, rhythmic exercise or yoga can help you reduce the stress of caring and boost your mood and energy levels. Take a walk or jog outside daily.

- ***Plan your own care :*** Visit your doctor for regular check-ups and pay attention to the signs and symptoms of excessive stress. Talk it over to your good friends.
- ***Ask for help :*** Reach out to other members of the family, friends or volunteer organi-sations to help you with daily load of caregiving.
- Set aside a minimum of 30 minutes everyday for yourself.

Do whatever you enjoy, whether it is reading, gardening, knitting, playing with pets or watching T.V. Listen to music that lifts your mood.

- ***Find ways to Pamper Yourself :*** Small luxuries can go a long way in relieving stress and boosting your spirits. Have candle light dinner, take a warm shower, get a manicure done, buy fresh flowers for the house, dance to your favourite music, read funny books or watch a comedy serial to laugh.
- Invite friends and relatives as it is difficult for you to leave the patient alone.
- ***Eat well :*** Eat fresh fruits and vegetables, whole grains, beans, lean protein and healthy fats such as nuts, almonds, walnuts etc. Sleep well.
- Update your caregiving skills and find new ways of coping with Alzheimer Disease. Join a support Group for Alzheimer disease. You will find that you are not alone and learn from the experiences of others who are or have faced same challenges.
- Taking care of loved one with Alzheimer Disease is not an easy journey. Be healthy and capable, to take care of yourself and the one

who now needs you more than they ever had in the past. Always remember that everything is happening with the will of God. When we leave everything in God's hand, we eventually see God's hand in everything. Have faith in the supreme energy. Trust him and trust yourself. Journey of life will be much easier and these divine thoughts will keep you relaxed.

Q.51. What are the simple health strategies that may lower the risks of Alzheimer disease and prevent complications from other health problems?

Ans : Taking care of your overall health by eating well, doing regular exercise, getting proper sleep, rest, staying active will give a person physical and mental advantages one needs to cope up with Alzheimer disease. Research has show that Alzheimer Disease may be prevented with right lifestyle choices.

- ***Right Eating :*** Research in recent years has found that our diets have a profound impact on our brain.
  - (a) Have lots of fresh fruits and green vegetables as they are rich in antioxidants that can prevent oxidative damage to the brain cells.
  - (b) Have nuts in your diet. Although nuts are higher in calories because of their fat content, they are also rich in nutrients that may help guard against Alzheimer. eg. Walnuts are rich in omega 3 fatty acids.
  - (c) Limit your fats and cholesterol and maintain a healthy body weight.

(d) Talk to your physician about taking certain vitamins, minerals and herbal supplements associated with brain health.

(e) Flax seeds and Tuna fish also help.

(f) Make powder of 60 grams each of mishri and desi saunf and 70 kernels of desi almonds. Take ½ a spoon with a cup of warm milk preferably at bed time.

- ***Physical Exercise :*** Research also indicates that getting plenty of physical exercise, eating a proper diet as well as quitting smoking and lowering blood pressure, can improve blood flow in brain, which can benefit brain cells to function properly. Walking is good for brain.

  Before starting any exercise programme, check with your doctor first and get recommendations about the type of activities you can do and those you should avoid.

- ***Keep the Brain Active :*** More and more researchers are now realising that keeping the brain active may help to slow down the cognitive decline.

  Whether it actually prevent Alzheimer remain uncertain, but it does appear to slow down the progress of the disease. Numerous activities can stimulate the brain. Among the best is reading, which stimulates several parts of the brain and strengthen synapses between neurons.

  Other mind stimulating activities include crossword puzzles, writing, playing games that require reasoning, judgement and memory games like Sudoku. Also practice 5 words : who, what, where, when and why for all situations.

Backward counting also helps. Write one page every day with the less used hand (Lt. hand for Rt. handed person).

- ***Maintain an active Social Life*** and spend quality time with family and friends. A study from Harvard school of Public Health reported that men and women who remain socially connected with friends and family had sharper memories.
- ***Surf the WEB :*** Searching the internet may be good for brain. Researchers at the University of California, Los Angeles, found that surfing the web triggers key centres in the brain involved in decision making and complex reasoning.
- ***Stay Busy :*** Do some voluntary work to stay active and busy as volunteers job is both stimulating for the mind and nourishing for the soul.

  Any task that requires complex, decision making helps in brain stimulation. Do things that challenge your creativity and make you feel productive like gardening, writing, drawing or playing an instrument etc.
- ***Learn new things :*** Expand your horizon and learn new things. It could be a new language, a new hobby or computer skills.
- Limit unhealthy mental habits like worrying and learn to overcome negative thoughts. Keep stress under control.

Q.52. My father has had Alzheimer for one year. Can he still make a will or sign a power of Attorney?

Ans : Power of Attorney is a legal document in which one person gives another person the power to handle his/her financial affairs. This power can only be given when the person is mentally capable of understanding what he or she is doing. For this reason, it is important for anyone who has been given diagnosis of Alzheimer, to consider having a power of Attorney drawn up as soon as possible. A doctor's advice may be saught if there is any doubt about a person's mental capacity.

A power of Attorney will give the receiver considerable power over the Alzheimer Disease patient's finances. So it is important to choose someone that the patient trusts and who is capable of making judgements in his/her interest. Usually a husband, wife choose each other or one of their children. It is possible to appoint joint attorneys too.

Making a will or signing a power of Attorney all depends on your father's mental capabilities. If you are worried about your father's competence, to avoid problems in future it may be wise to consult a doctor or solicitor to ensure that your father still has a testamentary capacity. For a will to be valid, your father will need to be able to understand what a will is, be aware of the size of his assets and be aware of the person who may have a claim to his finances. In order to sign a will or power of Attorney, your father also needs to understand at that time, that he is giving power to someone else to manage his affairs.

Best is to consult a lawyer who specialises in issues affecting the elderly people with Alzheimer Disease.

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Care Of Caregiver

Give Care...
who cannot care for themselves

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