

# An Introduction to Dementia (Alzheimer's, others)

A presentation from **Dementia Care Notes**

<http://dementiacarenotes.in>

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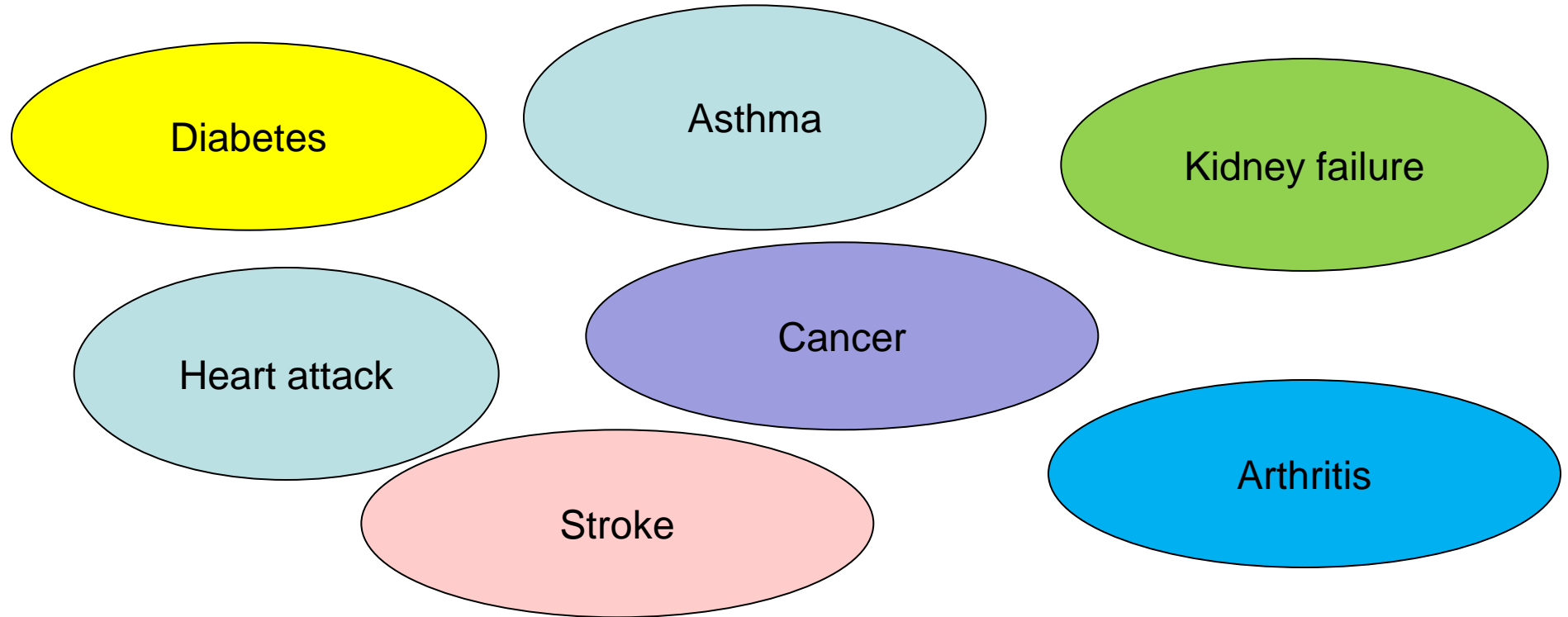
# Scope of this presentation

In this presentation, we provide an overview of dementia:

- basic facts about dementia and its prevalence
- how dementia affects patients and people around them
- how we can help reduce the patient distress and caregiver burden

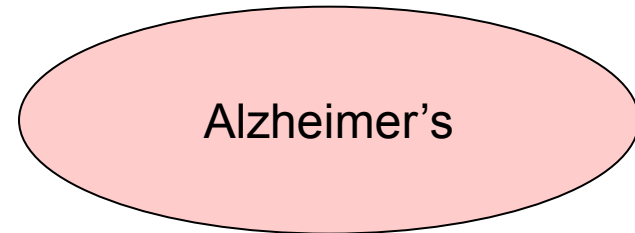
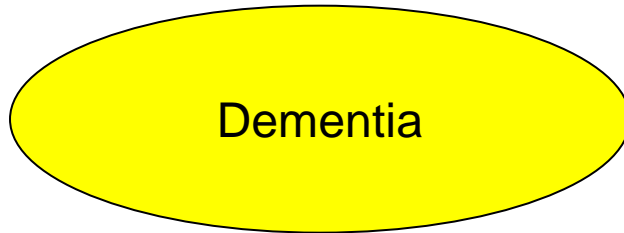
Note: This presentation was prepared for use by persons conducting dementia awareness programs in India. It can also be used by laypersons to get an initial understanding of dementia. While it contains information useful for anyone interested, it includes data and examples from India. This material is not a substitute for medical advice.

# How familiar are you with... (symptoms, causes, treatment)



It is likely that you have heard of most of these diseases, and are familiar with the symptoms or impact of the diseases

# How familiar are you with... (symptoms, causes, treatment)



Fewer people are familiar with “dementia” or “Alzheimer’s Disease”, their symptoms and treatment. However, dementia is prevalent, and on the rise in all countries, and impacts both patient and family adversely for many years.

# When we see strange behaviour (especially in the elderly)

- Repeats himself/ herself?
- Seems paranoid, suspicious, agitated for no reason?
- Keeps forgetting?
- Withdraws from people? Seems depressed?
- Seems confused?

**Do you think they are all normal  
ageing related difficulties?**

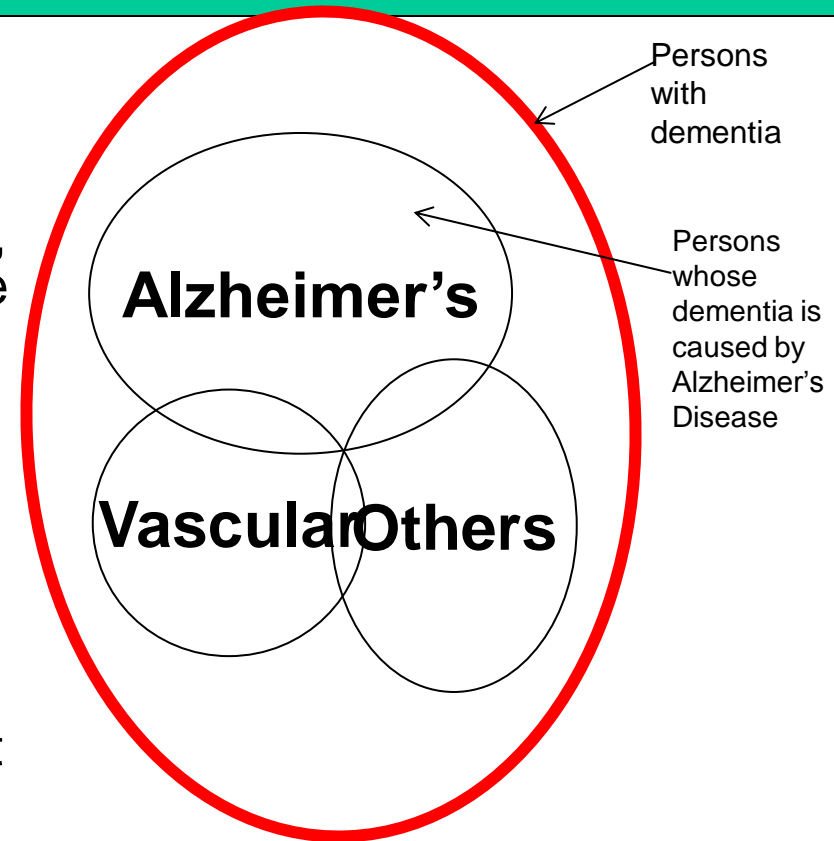
# What is Dementia

- Dementia is a general term used for progressive loss of brain functions that affect the ability to live and increase dependence
- Dementia is NOT part of normal ageing
- Dementia causes memory loss
- It affects thinking, speaking, and making decisions
- It interferes with the ability to perform normal activities of daily living (shopping, handling finances, driving, personal hygiene)
- Persons start behaving differently (includes insomnia, wandering, apathy, and aggression)
- In its final stages, dementia makes the patient fully dependent

# Types of dementia

There are many diseases that cause the group of symptoms called “dementia”

- Alzheimer’s, Vascular, Frontal lobe, Lewy Body, and other such **irreversible dementias** are due to physical changes in the brain.
- Alzheimer’s Disease is the most common cause of dementia (50-75%)
- Dementia can also occur after strokes, or because of other abnormalities in the brain
- A person can have more than one type of dementia
- Some causes of dementia respond to treatment (Vitamin B12 deficiency, hypothyroidism, depression)-these are called **reversible dementias**



*(Illustrative figure only; proportions do not represent % of various types of dementia)*

# Who gets dementia

- Dementia knows no social, economic, ethnic or geographic boundaries. Dementia has struck some of the most intellectual and active persons:
  - Physics Nobel Prize winner 2009, Charles Kuen Kao
  - US ex-president Ronald Reagan, UK ex-Prime Minister, Margaret Thatcher
  - Authors Iris Murdoch, Terry Pratchett
- Typical onset is after the age of sixty-five, but in some cases dementia is seen in people in their 30s, 40s and 50s



# Dementia: prevalence

- Worldwide, one new case of dementia every seven seconds.
- U S A statistics: **Alzheimer's Association Report, 2010:**
  - Alzheimer's disease was the seventh-leading cause of death across all ages in the United States in 2006.
  - It was the fifth-leading cause of death for those aged 65 and older.
  - More than 20 percent of women reaching age 65 ultimately developed dementia (estimated lifetime risk ) (17% of men).
- In India, the dementia population in 2010 was estimated as 37 lakhs (3.7 million) (as per the Dementia India Report 2010)
- As life expectancy goes up, so does the impact of dementia on the population

# 10 Warning Signs

- Memory changes that disrupt daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, work and leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

(From Alzheimer's Association, <http://alz.org>)

# The Diagnosis of Dementia

- If you suspect dementia in yourself/ someone else, consult your GP, or a neurologist in any major hospital. Memory clinics are also available
- What the neurologist may do:
  - Understand your problems, current health, medical history
  - Do a neurological evaluation, check your memory, orientation, mental abilities by using tests (asking questions, making you draw/ write something)
  - Do blood tests to detect and treat reversible problems like hypothyroidism, vitamin B12 deficiency
  - Do brain scans (MRI, CT Scan, PET Scan)

# Understanding the role of neuron connections

## Game: Pass the packet

- Pass a packet (in the audience) from one end of the room to another, without anyone getting up. Note the time it takes for the packet to reach the end of the room.
- Now identify some characteristic that only half of the audience share (for example, people wearing spectacles). Repeat the “pass the packet”, but this time, only people meeting that characteristic may participate in passing the packet. Note the time it takes for the packet to reach the end of the room.

# Understanding the role of neuron connections

- When you compare the time taken by the two “pass the packet” games, as per the last slide, you will note that the second game took longer. This seems obvious, because the second time, fewer people were able to pass the packet, and the person passing the packet had to spend time figuring out whom to next pass the packet to.
- Our brain is a network of neurons. When we lose neurons because they die/ get damaged, it is more difficult and slower for our brain to process messages.

# The Brain

***What does the brain do?***

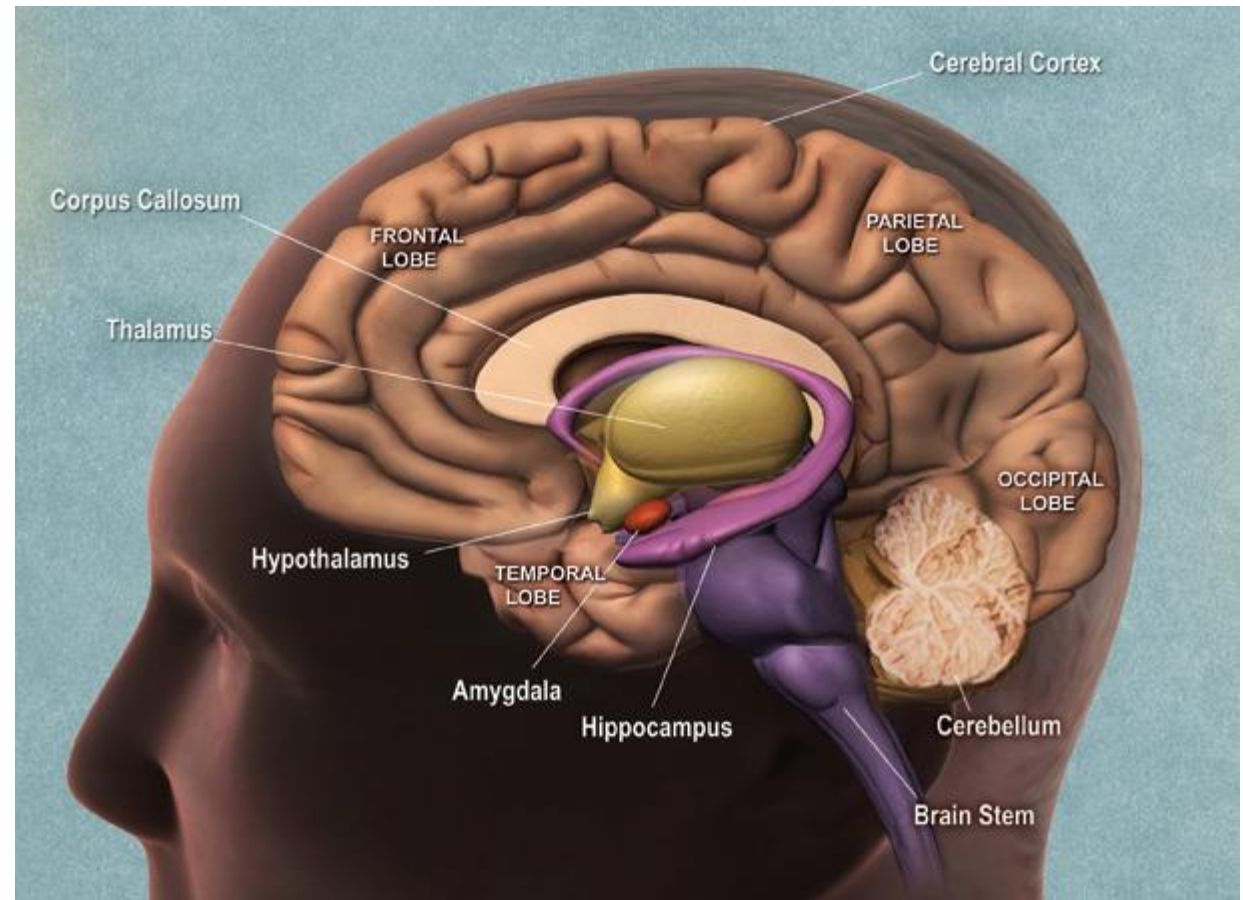


Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

# If your brain doesn't work...

- What activities are possible without the brain?

# Activity: Role Play

- Think of an activity you do every day.
- What are the steps involved?
- What happens if you forget one step?
  
- Examples of activities you can think about:
  - Making tea
  - Brushing your teeth
  - Driving
  - Talking on the phone
  - Reading the newspaper



# The Brain

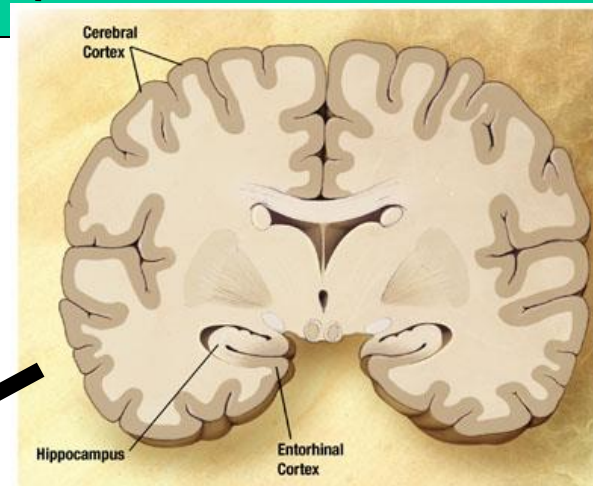
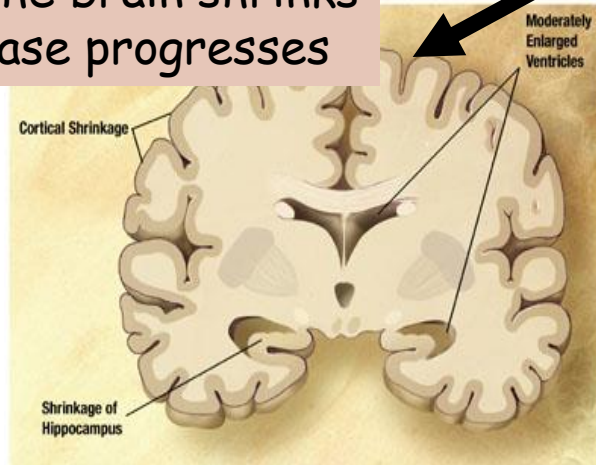
- Without the brain, you cannot:
  - Remember anything
  - Think, talk, listen, see
  - Use any part of the body
- Examples of problems faced if the brain is not functioning properly
  - Forgetting names of people
  - Forgetting where you are or what you want to do
  - Not noticing when it is hot or cold
  - Not being able to balance/ walk properly
  - Forgetting steps in daily activities
    - You may brush your teeth but forget to rinse your mouth
    - While making tea, you may forget to light the stove to boil the water

# Physical damage in Alzheimer's Disease (AD)

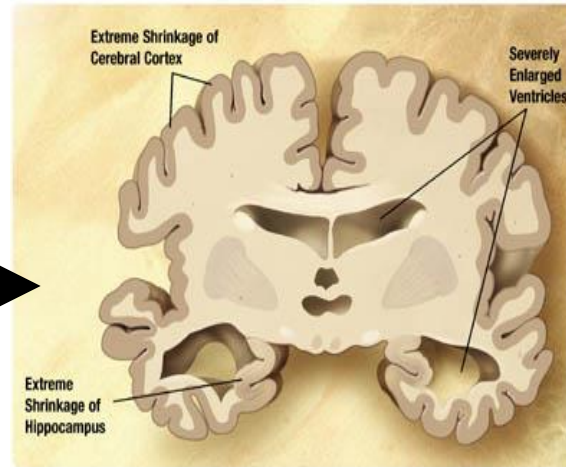
**Dementia is the name given to a set of symptoms related to progressive loss of brain function. Alzheimer's Disease is the most common cause of dementia.**

Note how the brain shrinks as the disease progresses

Mild to moderate



Pre-clinical



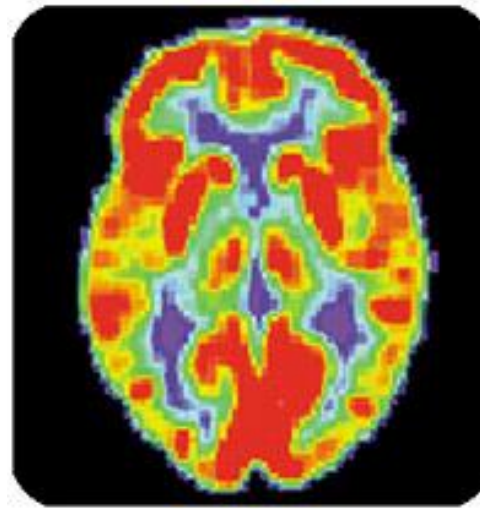
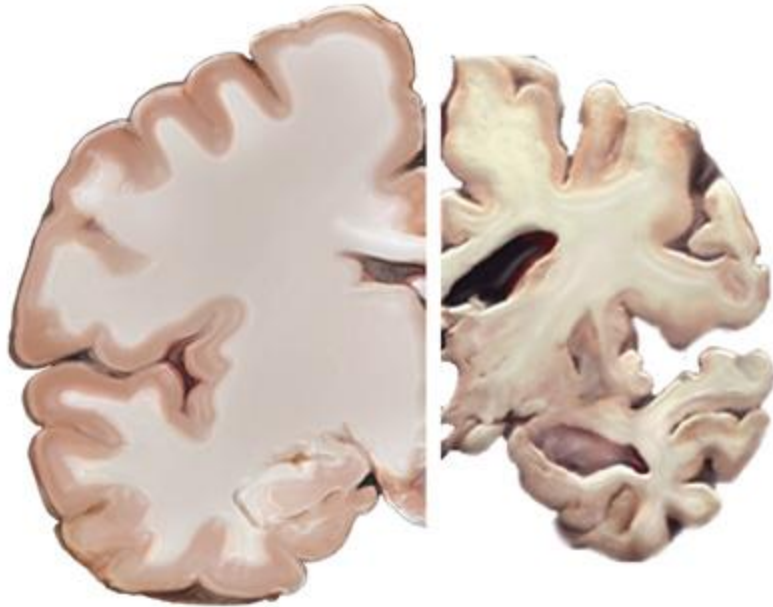
Severe

Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

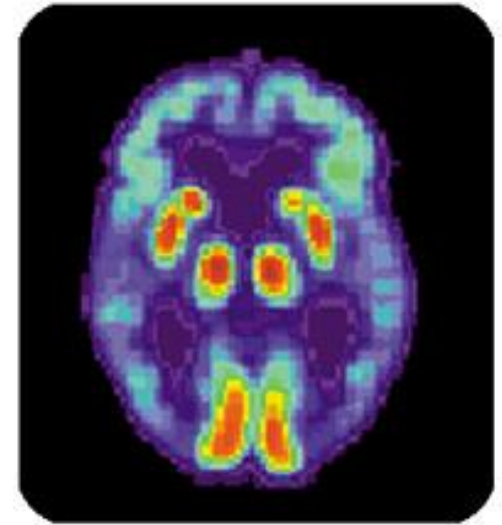
# Healthy brain versus Alzheimer's brain

Healthy  
Brain

Severe  
AD



Pet Scan of  
Normal Brain



Pet Scan of Alzheimer's  
Disease (AD) Brain

Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

# The neurons are damaged

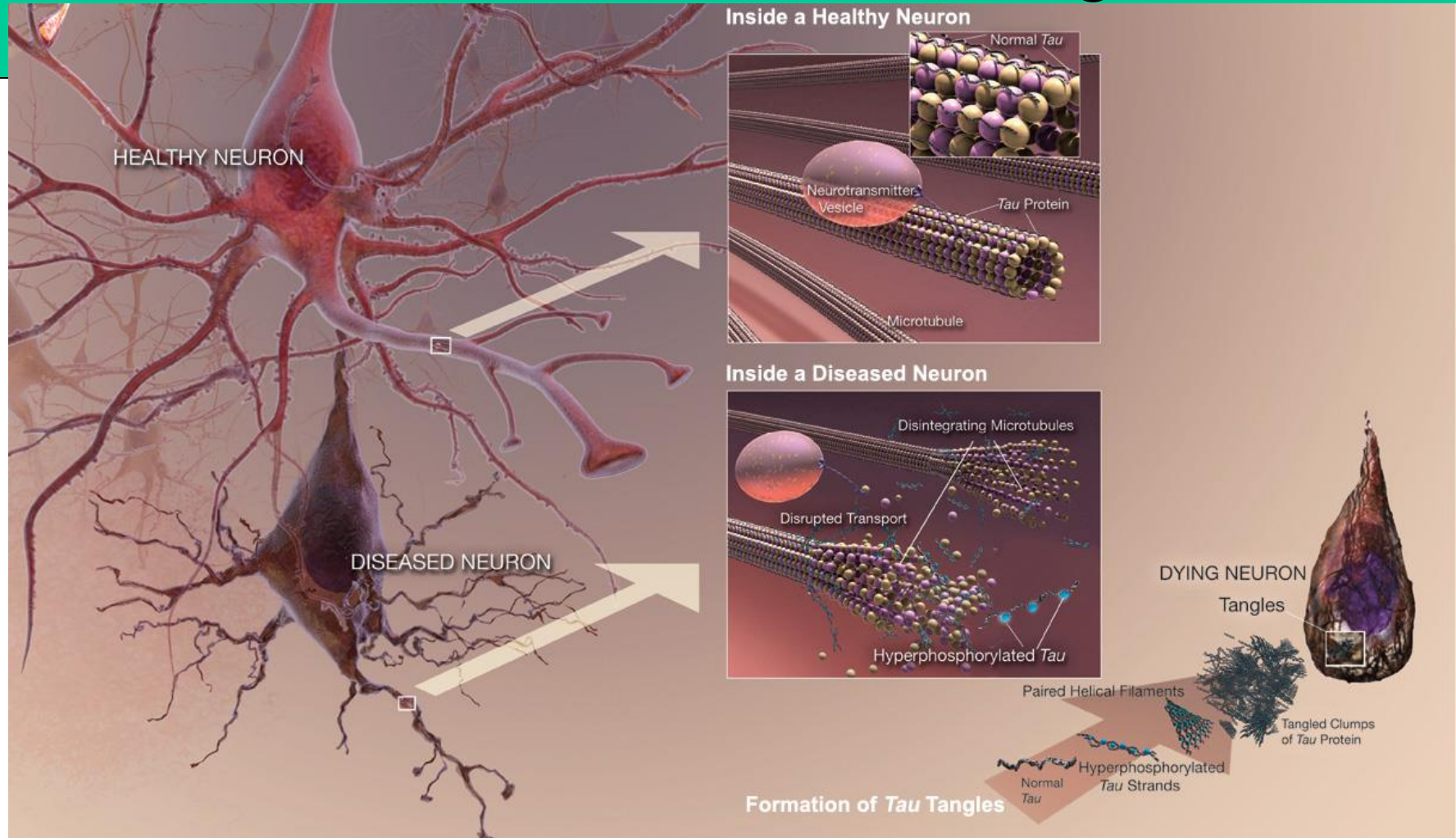


Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

# Dementia is NOT the same as normal ageing

<b>Normal Elder</b>	<b>Dementia Patient</b>
may forget part of an experience	forgets entire experiences
remembers the experience later	usually does not remember even later
understands written/ spoken directions	slowly loses ability to understand any directions
can use reminder notes	loses ability to use reminder notes
can take care of himself	loses the ability to take care of himself



# Dementia affects...

- Memory
- Insight
- Ability to Plan
- Information Processing
- Ability to Reason or Learn New Ideas
- Language Skills
- Filtering Systems
- Orientation & Spatial awareness
- Pain Perception
- Tolerance to Stress
- Control Mechanisms

# Dementia Behaviour

- Patient behaviour changes because of dementia problems
  - Patients cannot understand what is being said
  - They respond differently to situations
  - Often, they show strong emotions like frustration, rage, and withdrawal
- Sometimes, the patient's behaviour can harm the patient and/ or the people around the patient. This may happen because some need (physical, emotional) is not met.
- To prevent/ handle such behaviour, caregivers have to
  - Learn how to talk to patients and how to help them
  - Notice triggers than agitate/ upset patients and remove them
  - Adapt the homes so that they are suitable for patients

# Caregiver skills: Communicating

- Communicating strategies should take into account the reduced mental abilities
  - Use simple sentences, simple words.
  - Give only one instruction at a time
  - Use gestures, if necessary (point out, wave hands).
  - Do things that remind patient where she is and what she is doing or should do. Let patient imitate if possible
  - Give patient time to understand, and if necessary repeat. Do not get irritated
  - Do not question or contradict the patient, or get agitated
- Remember, patients may not understand the words, but they sense the expressions and mood, and know if you are irritated and angry.



# Caregiver skills: Useful tools

- Use routines- they give patients a sense of comfort
- Stimulate them to the extent that they find enriching
- Validation: When patients get agitated, say wrong things, complain--understand the underlying reason and address that
- Distraction often works
- Help patients stay oriented with their surroundings by cueing them about place, time, names, etc.
- Adjust environment to make it less threatening (add signs, reduce visual clutter, remove TV, mirrors)
- Use games, labelled albums, music, aromatherapy
- Many tools and tips are available in caregiver forums, where caregivers share situations and creative solutions

# Caregiver skills: Handling challenging behaviour

- Identify behaviours of concern
  - Focus on things that can harm patient, caregiver, society
- Find triggers
  - Use knowledge of patient, the activity that triggered behaviour, the environment, the type of communication, and the state of the patient health to do this
- Use creativity to define and implement a strategy
- Check effectiveness of strategy, and fine-tune it

# Stages of Dementia

- There are three stages in Dementia.
  - Early or Mild
  - Middle or Moderate
  - Late or Terminal stage
- Dementia may last anywhere from a couple of years to as long as over a decade. It cannot be cured, and keeps getting worse.
- Death is usually due to co-morbidities
- Understanding the stages of dementia helps us plan for them

# Early stage of dementia

- The patient
  - Faces short-term memory problems
  - Is unable to do complex things (like planning a party)
  - Is unable to learn new things
  - Often gets disoriented about date, place
  - May wander
  - Often gets frustrated, repeats things, gets angry, violent
  - Acts suspicious, angry, restless
  - May withdraw from activities (as lacks confidence)
- A lot of small things keep going wrong

# As dementia progresses...

- The patient
  - Often forgets recent events, remembers distant past better.
  - Is confused about time and place
  - Wanders out, gets lost
  - Sees or hears things that are not there
  - Become very repetitive
  - Often neglects personal hygiene and appetite
  - May act irritable, anxious, self-centered, inflexible
  - May become passive and withdraw
  - Needs help in various activities, like:
    - Bathing and hygiene, toilet, wearing clothes, combing hair, walking, getting up
  - May sometimes lose control over urine/ bowels

# Final stage of dementia

- The patient
  - Is unable to recognize family members
  - Is unable to talk, does not understand anything
  - Sleeps most of the day, seems unaware of surroundings
  - Becomes bed-ridden, totally dependent
  - Has difficulty in swallowing—food goes into lungs, or patient chokes
  - Gets infections easily
  - Becomes incontinent (loss of control on bladder, bowels)
  - Is withdrawn, insecure, may feel threatened most of the time.
- The goal of caregiving is comfort

**Unlike many other conditions, dementia often involves a long goodbye**

# Some Medical Facts about Dementia

- Dementia is NOT infectious
  - (you cannot “catch” it like you catch a cold)
- It usually affects older people (> 65 years)
  - “early onset” happens if it affects people < 65 years, such as 30, 40, 50. This is still rare
  - As many diseases can cause dementia symptoms, the risk factors vary.
  - For Alzheimer’s Disease, family history increases risk/probability, and so do some genes (like ApoE4 ). Very few cases are caused by “deterministic” genes running in a family; For details, see:  
[http://alz.org/alzheimers\\_disease\\_causes\\_risk\\_factors.asp](http://alz.org/alzheimers_disease_causes_risk_factors.asp)

# Some Medical Facts about Dementia

- Only a few causes of dementia are reversible
- Most dementias are irreversible. As per current medical knowledge:
  - There is NO known prevention
    - though good diet, exercise, and keeping the brain active might delay symptoms
  - There is NO cure
    - Some medicines can partly delay some symptoms (not stop progression), especially if given in early stages of the dementia
  - The progression of such dementias CANNOT be stopped
    - The patient will keep getting worse, till he/ she stops understanding everything and is bed-ridden



# What may help delay...

Doctors suggest normal good health practices, such as

- Eat healthy diet (include fruits, vegetables)
- Exercise
- Keep brain active (no TV)
- Stay free of lifestyle diseases (High BP, diabetes, etc)
- Maintain an active social life
- Stay stress free

AND

- protect the head from injury

# Dementia Awareness in India

Dementia awareness is very poor in India. Some comments from studies done in India:

- Family members speak of weak brain, when they speak of it at all. They say it is natural phenomenon, as old age.
- People believe Dementia is associated with, indeed, caused by family neglect.
- When outsiders see patient yelling and wandering, and hear accusations of mistreatment, they say this is a 'Bad Family.'
- A caregiver quote: 'Family members think we are the cause for his illness - they think we deserve all that is happening to us.'

(Source of some quotes: [http://www.alz.co.uk/1066/qualitative\\_studies.php](http://www.alz.co.uk/1066/qualitative_studies.php))

**Caregivers must handle social stigma and blame in addition to disturbed behaviour of the patient**

# Multiple Facets of Dementia Care

Dementia is on the rise. More and more people are affected as patients and caregivers. We need to support dementia care through policies, facilities, and volunteer work.

- Research in dementia causes, treatments, risks, and in caregiver intervention effectiveness
- Spreading dementia awareness to enable earlier diagnosis and better support for patients and caregivers
- Ensuring availability of resources for diagnosis and treatment
- Providing financial aid: Dementia care often means loss of income for patient and caregivers. Financial problems are often faced.
- Caregiving support: The patient's wellbeing depends on the ability of caregivers to look after them.

# Multiple Facets of Dementia Care

- **Caregiver support:** Caregivers can be supported in multiple ways, such as
  - Training in caregiving skills
  - Support through support group meetings
  - Facilities like respite care and day care
  - Trained nurses and attendants to ease the work and stress of home-based care for patients
  - Home-based medical/ nursing services
  - Counseling and support for tough decisions that end-of-life cases involve, such as palliative care decisions
  - Dementia-care homes for patients who cannot be cared for at home

# The role of a caregiver

The caregiver role is critical for dementia care. We need to understand how deeply a dementia patient affects the family around him/ her.

- People caring for dementia patients may get sad or tired or upset
- People looking after their parents (who have dementia) may not spend enough time with their own children
- The family may not be able to take holidays, talk, go for movies
- Because of poor awareness of dementia,
  - the condition and its cause may not be diagnosed early
  - outsiders may think the problems are because of neglect, and they may blame and criticize
  - there may be fights and blame-games within the family

# What caregivers can do

- As a caregiver
  - Understand that the behaviour is because of dementia, and do not get upset when the patient acts strangely
  - Learn ways to talk to the patient, or handle problems like agitation
  - Avail of community support to share tips and reduce overwhelm
  - Do things with the patient that are fun (reading stories to the patient, seeing albums together, going for walks). Think of ways to help the patient remember things
- Remember, if the patient is less agitated/ helpless, caregiving is easier and more pleasant

Every patient is different in how fast dementia progresses, and the order of what gets affected

# What friends/ relatives/ neighbours can do

- As people around the caregiver
  - Help the main caregivers take a break and understand their moods
  - Run errands for them
  - Provide them emotional support
  - Do not make too many demands on the main caregiver
  - Do not criticize

# If you are concerned about dementia, you can...

- Join dementia awareness activities, such as walks
- Talk to others about dementia and caregivers, and help spread the “voices” of patients and caregivers
- Raise funds for/ do volunteer work in facilities that help patients and caregivers, such as day care, respite care.  
Helplines
- Get trained as a counsellor to support patients and caregivers
- Participate in drug trials/ fund research
- Support and lobby for policies to help the cause of elder care and dementia



# Summary

- Dementia is the progressive loss of brain functions that affects the ability to live and increase dependence.
  - It affects memory, the ability to understand and talk, and the ability to do things.
  - Many diseases can result in the dementia symptoms (Alzheimer's Disease is the most common)
  - Dementia usually (but not always) affects older people, but it is not a normal part of ageing
- Medical science is not certain about its causes or prevention
  - There is no cure for it
  - Remaining active and living healthily are recommended to reduce risk
- Caring for a dementia patient is very challenging.
  - Caregivers have to learn about dementia and caregiving skills
  - They often make major adjustments in their lives, including giving up jobs
- We can help by supporting patients and caregivers and volunteering for projects such as awareness campaigns and fund raising

# Thank You

For more information, resources, and caregiver stories, visit

## **Dementia Care Notes**

<http://dementiacarenotes.in>

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