

An Introduction to Dementia (Alzheimer's, others)

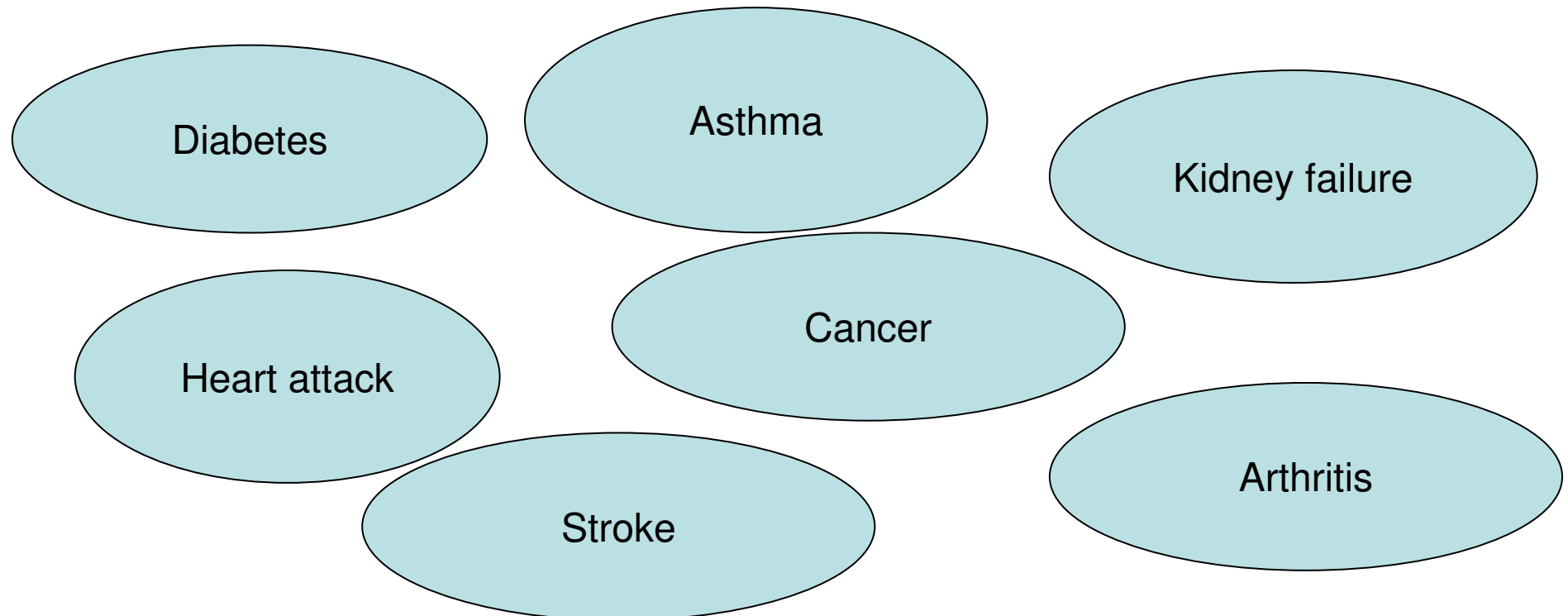
Scope of this presentation

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

This presentation is intended for people to get an initial understanding of dementia. It can also be used as material by trainers working in the area of dementia awareness. 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)

Dementia

Alzheimer's

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?**

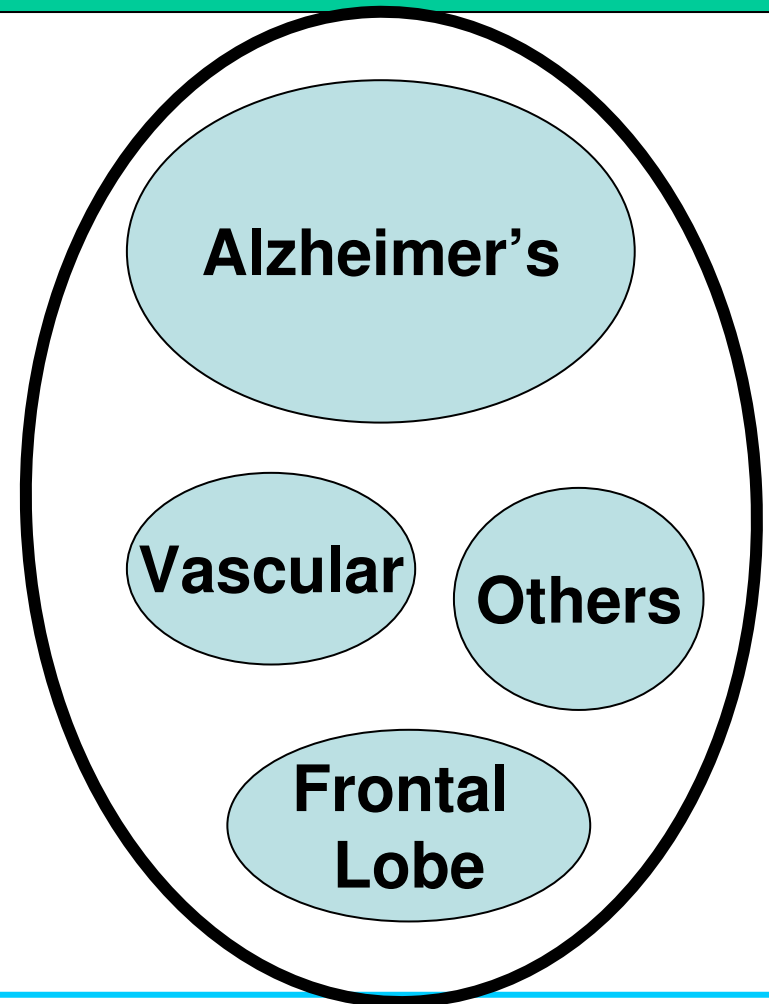
What is Dementia

- 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, taking decisions, maintaining bank accounts, 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 and have similar problems
- Alzheimer’s Disease is the most common dementia (60%)
- Patient can have more than one type of dementia
- Other types include dementia that occurs after strokes, or because of other abnormalities in the brain
- Some causes of dementia respond to treatment (Vitamin B12 deficiency, hypothyroidism, depression)-called **reversible dementias**



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 president Ronald Reagan, UK Prime Minister, Margaret Thatcher
 - Authors Iris Murdoch, Terry Pratchett
- Typical onset is after the age of sixty, but in some cases can even hit people in their 30s, 40s and 50s

Dementia: prevalence

- Worldwide, one new case of dementia every seven seconds.
- U S A statistics
 - HBO project: 54% have been touched by someone (living or deceased) who has Alzheimer's, and about 1/3 are worried about getting Alzheimer's
 - 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 is expected to reach six million by 2040
- As life expectancy goes up, the impact of dementia on the population goes up

10 Warning Signs

- Memory changes that disrupt daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at 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?

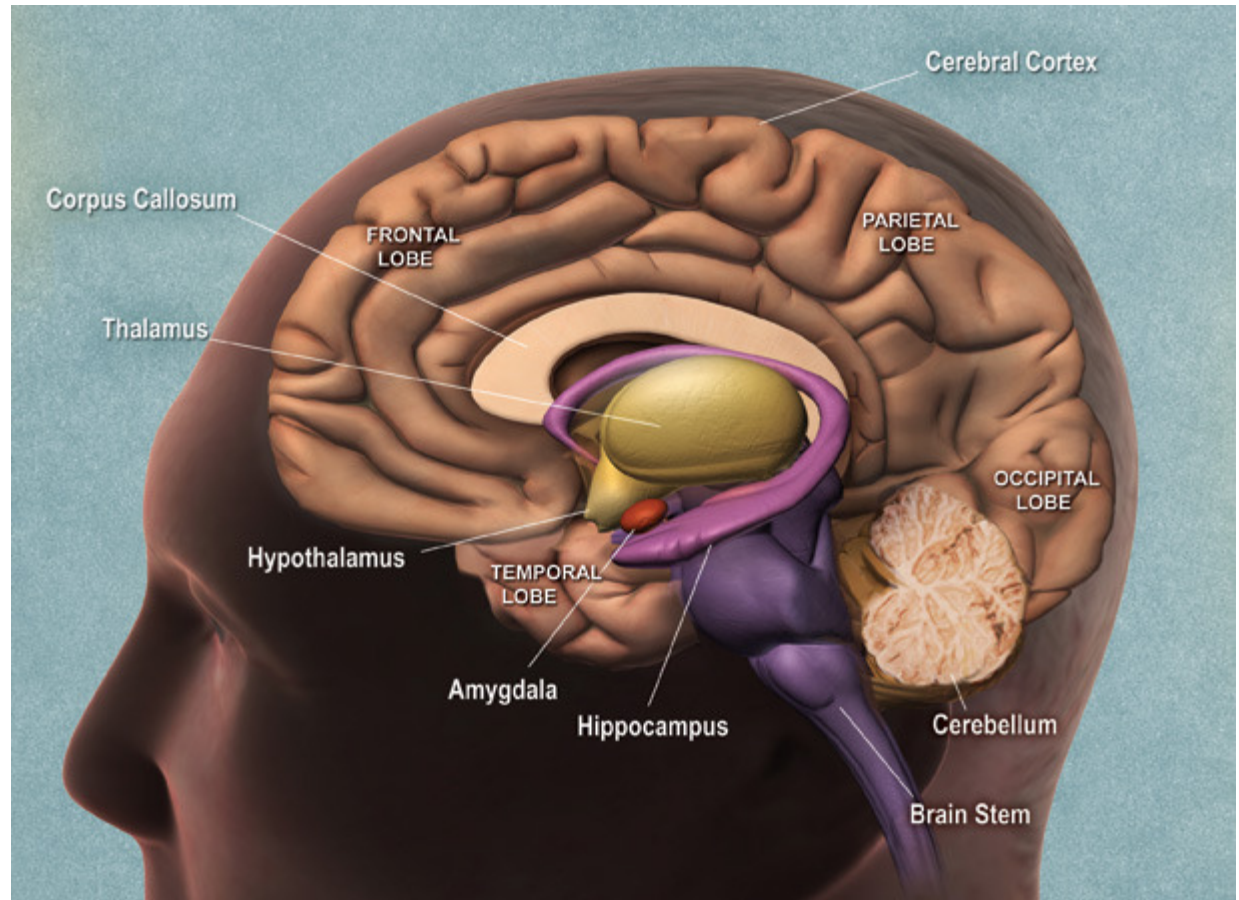


Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

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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

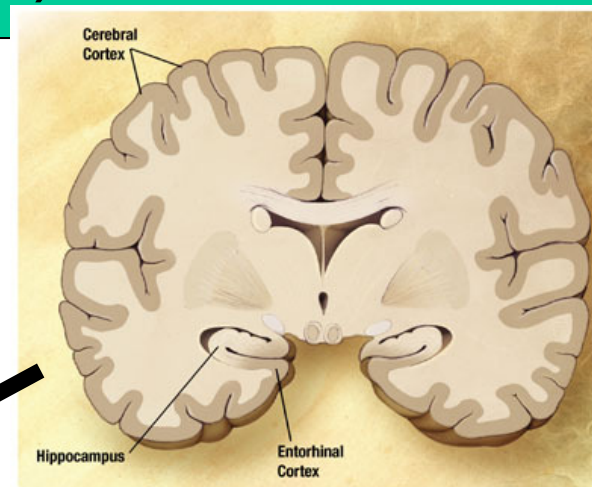
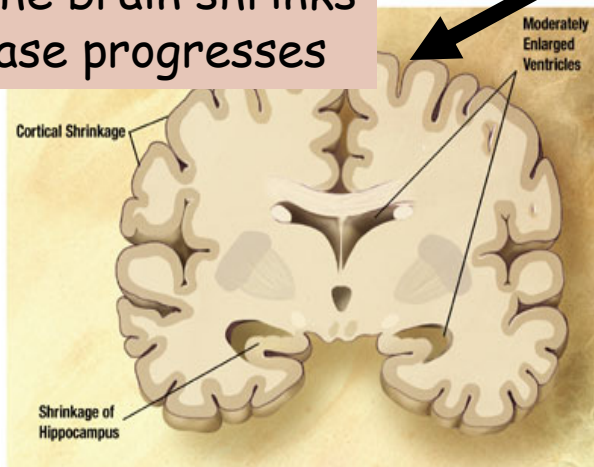
- As you may have realized/ known, without the brain, you cannot:
 - Remember anything
 - Think, talk, listen, see
 - Use any part of the body
- If the brain is not working properly, you will have problems all the time, like
 - Forgetting names of people you are talking to
 - Forgetting where you are or what you want to do
 - Forgetting steps in things you do every day,
 - For example, while brushing your teeth you may forget to apply toothpaste to the brush, or forget to rinse your mouth or close the tap after brushing the teeth
 - While making tea, you may forget to add tea or milk or even water, or forget to boil the water, or to light the stove or put off the stove after making tea.
 - Not noticing when it is hot or cold
 - Not being able to move your body properly
- Every activity you do, everything you notice, everything you think or remember requires a functioning brain.

Physical damage in Alzheimer's Disease (AD)

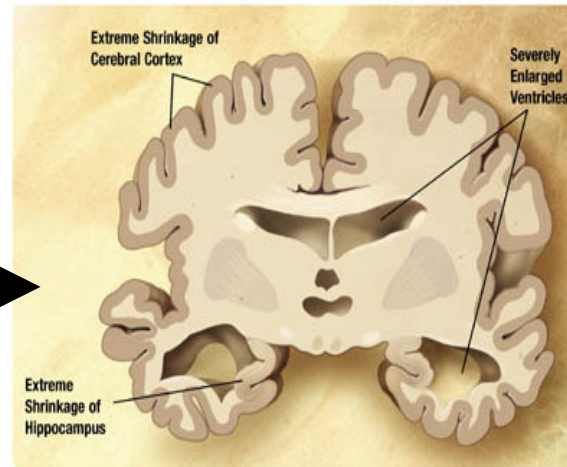
Dementia is the name given to a set of symptoms related to progressive loss of brain function. Alzheimer's Disease is the most common cause of dementia.

Note how the brain shrinks as the disease progresses

Mild to moderate



Pre-clinical

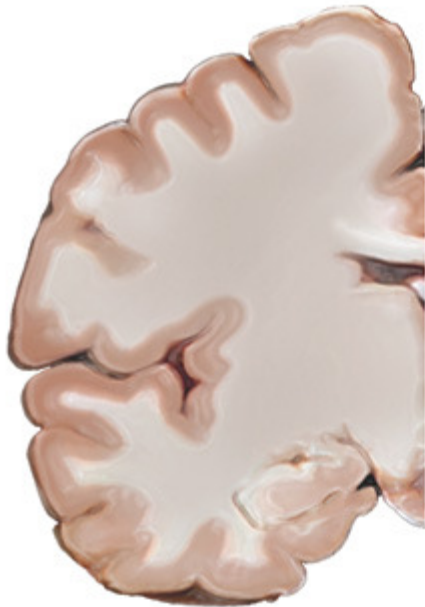


Severe

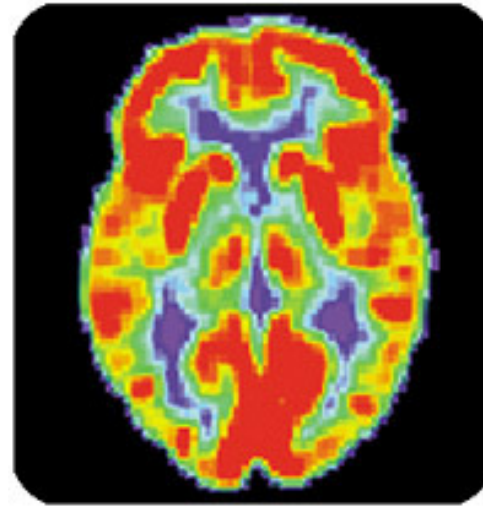
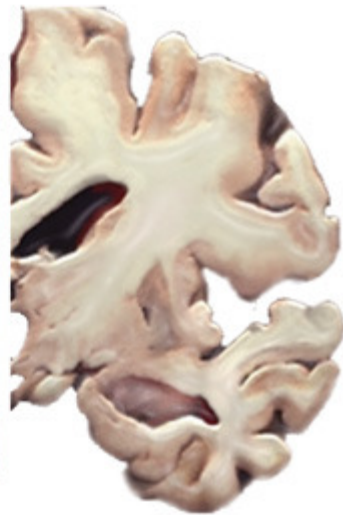
Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

Healthy brain versus Alzheimer's brain

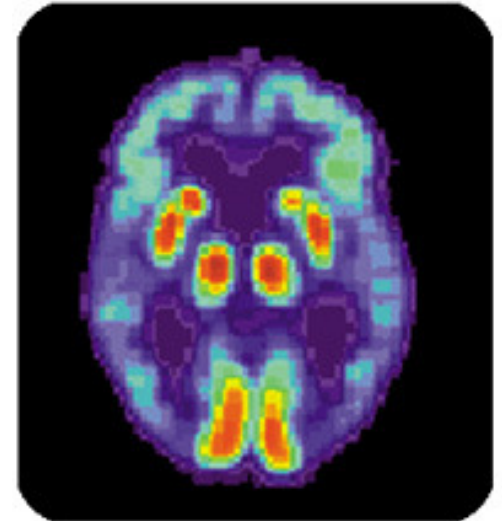
Healthy
Brain



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>)

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The neurons are damaged

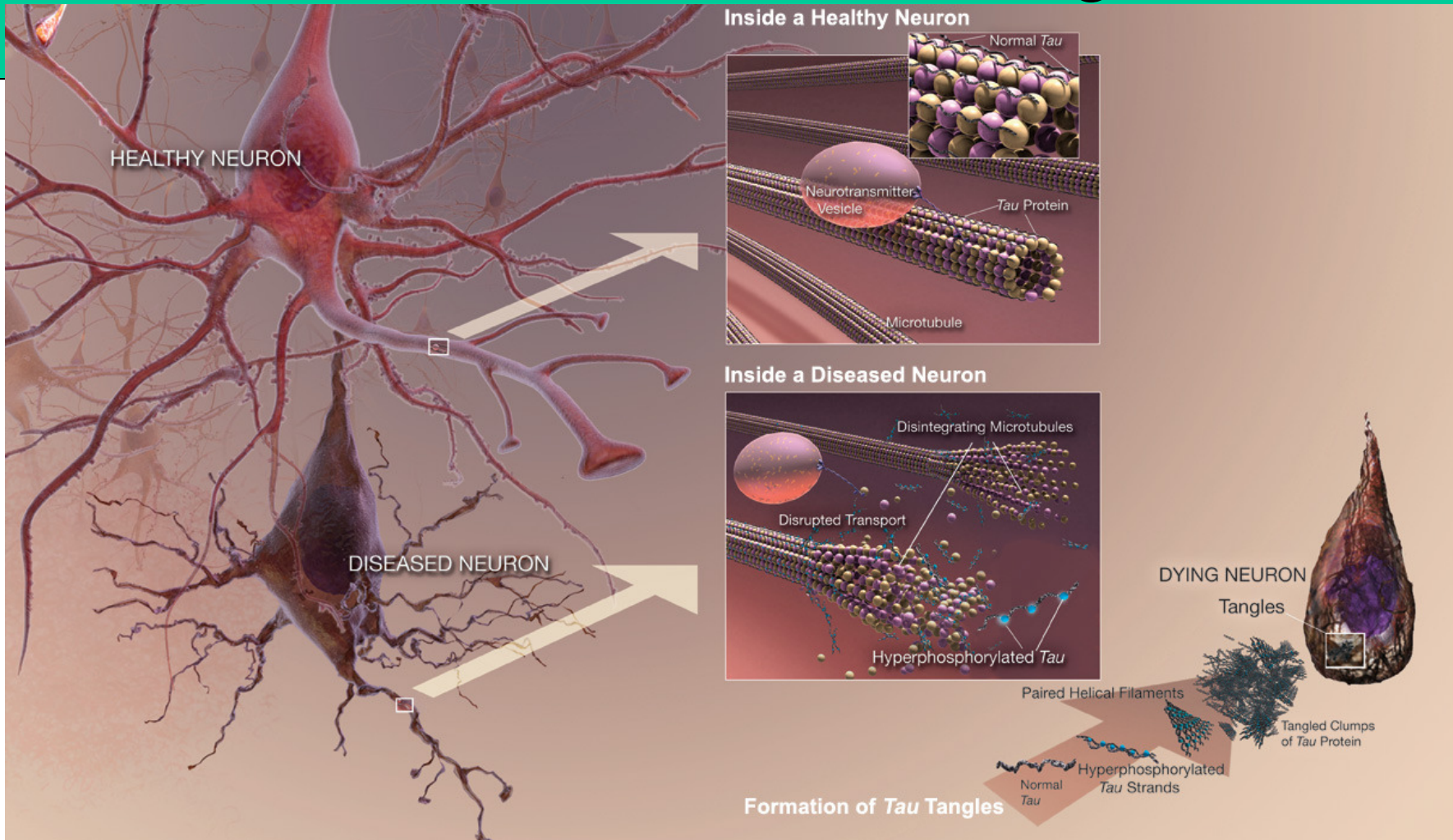


Image courtesy: ADEAR (Alzheimer's Disease Education and Referral Center, <http://www.nia.nih.gov/Alzheimers/Resources>)

Dementia is NOT the same as normal ageing

- A normal old person may forget part of an experience
 - A dementia patient forgets entire experiences
- A normal old person remembers the experience later
 - A dementia patient usually does not remember even later
- A normal old person understands written/ spoken directions
 - A dementia patient slowly loses ability to understand any directions
- A normal old person can use reminder notes
 - A dementia patient loses ability to use reminder notes
- A normal old person can take care of himself
 - A dementia patient 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

Challenging behaviour

- Some behaviour can harm the patient and/ or the people around the patient
- Such behaviour is a reaction to something that is not right for the patient
 - It generally occurs when a need is not being met.
 - The need may be a physical one
 - It may also be emotional or spiritual, such as the need for respect, love, or happiness.
- What you can do to prevent/ handle such behaviour
 - Communicate effectively with patients
 - Learn tools that are suited for dementia patients
 - Adjust the environment to make it less stressful and more enriching for them
 - Whenever the patient shows behaviour that can harm him/ her or caregivers/ community, understand the triggers and identify and implement strategies to handle the behaviour

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 can sense the expressions and mood, and will know if you are irritated and angry.

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

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 2-3 years to as long as 10-12 years, ending in death.
- Death usually due to co-morbidities

Early stage of dementia

- Faces short-term memory problems
- Unable to do complex things (like planning a party)
- Unable to learn new things
- Often disoriented about date, place
- May wander
- Often 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

- 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

- Bed-ridden, totally dependent
- Unable to recognize family members
- Unable to talk, does not understand anything
- Sleeps most of the day, seems unaware of surroundings
- Has difficulty swallowing—food goes into lungs, or patient chokes
- Gets infections easily
- May become incontinent (loss of control on bladder, bowels)
- Withdrawn, insecure, may feel threatened most of the time.
- Comfort is the goal

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 cause dementia symptoms, the risk factors vary
 - For Alzheimer’s Disease, family history increases risk/ probability, and so do some genes (like APOE-e4). Very few cases are caused by “deterministic” genes running in a family; see: http://alz.org/alzheimers_disease_causes_risk_factors.asp for details)
- Only a few causes of dementia are reversible
- Most dementias are irreversible
 - 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

- Healthy diet (include fruits, vegetables)
- Exercise
- Keep brain active (no TV)
- Stay free of lifestyle diseases (High BP, hyperlipidemia, diabetes)
- Active social life
- Stay stress free

AND

- protect the head from injury

Dementia Awareness in India

Comments from studies done in India:

- 'Family members think we are the cause for his illness - they think we deserve all that is happening to us.' (quote from caregiver)
- Family members speak of weak brain, when they speak of it at all. They say it is natural phenomenon, as old age.
- When outsiders see patient yelling and wandering, and hear accusations of mistreatment, they say this is a 'Bad Family.' ('the old person receives inadequate respect or support from children.')
- People believe Dementia is associated with, indeed, caused by family neglect.
- Behavioural symptoms of dementia; wandering, calling out, making accusations; may be taken by outsiders as evidence of neglect or abuse.

(Source of some quotes: 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

As the number of people impacted by dementia as patients/ caregivers is rising, multiple facets of dementia care must be supported through policies and by work of volunteer organizations.

- Society needs to become **aware of dementia** so that it supports dementia patients and their caregivers, and so that patients/ caregivers notice symptoms early and seek early diagnosis
 - **Early onset dementia** cases require special **counseling** and **financial support**, because the patient/ caregiver often lose their ability to generate income
- There should be **research** in dementia.
- **Diagnosis and treatment for dementia** should be easily available, and **doctors and nurses sensitized** to what patients and their caregivers need
- Patients/ caregivers need support for **planning legal and financial matters**
- Caregivers need support in multiple ways, such as
 - **training in caregiving**,
 - 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**.
 - Good **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 you 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 you 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

Dementia-related support

- Join dementia awareness activities
 - Participate in awareness walks
 - Talk about dementia and share experiences
 - Interview patients and caregivers for articles, movies, etc
 - Script and act in plays that sensitize people about dementia and caregiving
- Volunteer for, and raise funds for systems around dementia patients
 - Day care, respite care, specialized facilities
 - Telephone helpline, self-help groups
 - Train caregivers and nurses
 - Provide Legal and financial assistance
 - Help in dementia facilities by performing activities such as group painting, plays, etc
 - Counsel and emotionally support patients and caregivers
- Fund or participate in research projects in dementia, and drug trials
- Support and lobby for policies to help the cause of elder care and dementia

Summary

- Dementia is a general term used for progressive loss of brain functions that affect the ability to live and increase dependence. It affects memory, the ability to understand and talk, and the ability to do things. There are many diseases that result in the dementia symptoms (Alzheimer's Disease is the most common)
- Dementia usually (but not always) affects older people and often results in death from co-morbidities
- It is more common than we think, and often confused with old age
- Caring for a dementia patient often needs major adjustments in the family. Caregiver stress is a big problem.
- Medical science is not certain about its causes or prevention, and there is no cure for it, but general healthy practices and remaining active mentally and physically can delay the impact of dementia
- We can help patients by learning enough about dementia and how to interact with the patients, and helping them live a life of dignity
- We can help caregivers by performing errands for them and providing emotional support
- We can also help by volunteering for projects such as awareness programs, or providing funds

Thank You

More resources on dementia are available from the creator of this presentation at:
<http://swapnawrites.com>

About this presentation:

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