

# Coping with a Loved One's Dementia

This one-time, virtual class is designed for family or a significant other of a Kaiser member who has been diagnosed with Dementia or Mild Cognitive Impairment.

The class provides an overview of dementia, resources, and communication strategies to help those caring for someone with cognitive impairment/dementia. In this class you will:

- Gain an understanding of the diagnosis and progression of dementia/MCI.
- Learn behavior and communication skills to assist your loved one
- Understand the role of Kaiser Permanente and other care providers.
- Learn about community resources available for support of both the patient and family.

Additional Kaiser Permanente and community resources can be found on the Continuing Care Services Website: <a href="http://continuingcare-sandiego.kp.org">http://continuingcare-sandiego.kp.org</a>



Coping with a Loved One's Dementia

Virtual Class
Meets every 1<sup>st</sup> and 3<sup>rd</sup>
Tuesday of every month.
10-11 am

- ✓ There is no need to register for the class.
- ✓ Simply go to

  positivechoice.org/
  Coping-With-a-LovedOnes-Dementia
- ✓ Click on the follow the click to log into the class.

Questions?
Contact the Neurology
Department (877) 236-0333



# Memory Evaluation and Diagnosis

**Diagnosis**: Other diseases that cause the same symptoms as Dementia must be ruled out before a probable diagnosis of Dementia can be made. The diagnosis is made by completing each of the following:

- Written and Verbal Memory Testing (MMSE or MOCA)
- Imaging Study
- Personal/Family Report
- Laboratory Tests for memory problems include:
  - Complete blood count
  - Thyroid function
  - Liver and Kidney Function
  - Vitamin B12 level
  - Level of Inflammation in the blood
  - Calcium
  - Level of Salts- including sodium, potassium

**Treatable Conditions**: Some degree of recovery is possible with other medical conditions that mimic dementia.

- ❖ Brain Tumors or Subdural Hematomas: tumors or collections of blood that press on the brain and cause memory problems.
- ❖ Metabolic Dementia vitamin deficiencies, thyroid, or electrolyte abnormalities.
- ❖ Depression can cause or worsen cognitive impairment. It can also occur in conjunction with dementia.
- Overuse or abuse of medications, especially sleeping pills, tranquilizers, and antidepressants.

In order to meet the criteria for dementia diagnosis, an individual's cognitive impairment needs to be severe enough to affect one or more of the following functions:

- Memory: short term and long term
- Cognition: thinking, planning, reasoning, judgement and language skills
- Behavior: changes to mood or personality
- Physical Function: motor skills, balance, gait and senses



## Mild Cognitive Impairment (MCI):

most commonly defined as subtle but measurable memory disorder. A person with MCI experiences memory problems greater than normally expected with aging, but does not show other symptoms of dementia, such as impaired judgment or reasoning.

**Dementia**: a loss of brain function which involves the decline of memory, reasoning and other mental abilities. This decline is progressive and eventually impairs the ability to carry out the tasks of daily living

# Types of Dementias

<u>Vascular or Multi-Infarct Dementia</u>: this type of dementia results from extensive narrowing and blockage of the arteries that supply blood to the brain or from strokes caused by an interruption of blood flow to the brain.

Lewy Body Dementia: Lewy bodies are abnormal protein deposits that disrupt the brain's normal functioning; found in an area of the brain stem where they deplete the neurotransmitter dopamine. When widespread within the brain, Lewy bodies cause symptoms similar to Alzheimer's. They can also be associated with the tremor and

rigidity of Parkinson's disease. Hallucinations are common in people with LBD.

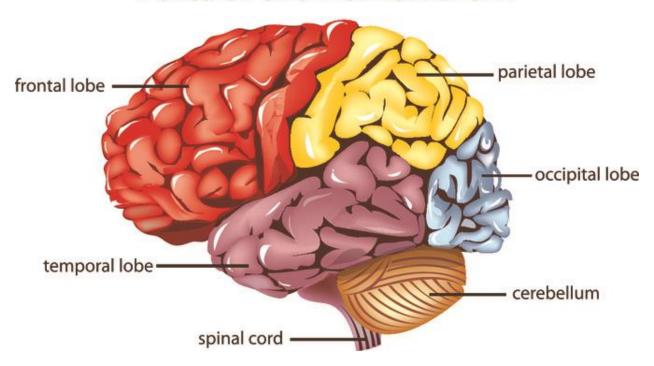
<u>Parkinson's Disease</u>: Parkinson's is characterized by stiffness of the limbs, tremor, speech impairment, a shuffling gait. Dementia can develop with a slowing of the thought process, confusion, and memory problems.

<u>Frontotemporal Dementia</u>: this dementia is more uncommon. It is characterized by disturbances in behavior and personality, and eventually memory loss. Pick's disease is a form of frontotemporal dementia.

Alzheimer's Dementia: Alzheimer's disease is the most common form of dementia, affecting about 4.5 million Americans. Alzheimer's is a progressive neurodegenerative disease that involves the loss of nerve cells in the areas of the brain vital to memory and cognitive skills. This loss is associated with the development of plaques and tangles. There are also lowered levels of brain chemicals that carry messages back and forth between nerve cells. Alzheimer's gradually destroys a person's memory and ability to learn, reason, make judgments, communicate, and carry out activities of daily living.



# Parts of the Human Brain



**Temporal Lobe:** stores new information, memory, language

Frontal Lobe: problem-solving, behavior, judgement, executive functioning

Parietal Lobe: organizes your body in space, perception, written language, word and thought

formation

Occipital Lobe: vision

**Cerebellum**: fine motor skill, balance, coordination **Brain Stem/Spinal Cord**: swallowing, movement

During the preclinical stage of Alzheimer's disease, people seem to be symptom-free, but toxic changes are taking place in the brain. Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain, and once-healthy neurons stop functioning, lose connections with other neurons, and die. The damage initially appears to take place in the hippocampus, the part of the brain essential in forming memories. As more neurons die, additional parts of the brain are affected, and they begin to shrink. By the final stage of Alzheimer's, damage is widespread, and brain volume has shrunk significantly. (<a href="www.alzsd.org">www.alzsd.org</a>)



# Stages of Dementia

#### Mild

- Individuals may be able to function independently, may drive and participate in social activities
- Individuals usually have difficulty finding word/name for items, decreased ability to remember names of new people
- Performance issues in social or work settings noticeable to family/friends
- Losing or misplacing items
- Individuals may appear more apathetic or less willing to try new things
- Become more forgetful with recent events or become confused or disoriented to time and place

#### Moderate

- Individuals become more confused, forgetting recent events or not being able to recall current date and time
- Often become lost more easily or become prone to wandering
- Show poor judgement, making poor decisions, more difficulty deciding what to wear
- Usually retain substantial knowledge about themselves and can recall distant memories
- Usually require no assistance with eating or using the toilet

## Severe

- Individuals lose their capacity for recognizable speech, although words/phrases may be occasionally uttered
- Individuals need help with eating and toileting
- Individuals lose their ability to walk without assistance, ability to sit upright, ability to smile and hold their head up. Swallowing becomes impaired.

Alzheimer's disease typically progresses over 2 to 20 years, and individuals live on average for 8 to 10 years from diagnosis.



# **Treatment for Memory Disorders**

# **Memory Stabilizers**

\*Side effects: may cause nausea, vomiting, dizziness, and loss of appetite

- Aricept (Donepezil)
- Galantamine (Reminyl)
- Exelon (Rivastigmine) Pill or Patch
- Namenda (Memantine)

## Medications for Depression: (low mood and irritability)

\*Side effects: Nausea, insomnia, dizziness & shaking of the hands.

- Zoloft (sertraline)
- Prozac (fluoxetine)
- Paxil (paroxetine)
- Effexor (venlafaxine)
- Wellbutrin (bupropion)
- Desyrel (trazodone)

**Antipsychotic Medications**: for hallucinations, delusions, aggression, agitation, hostility or uncooperativeness

\*Side effects: sleepiness, dizziness, slowed movements or tremor. "Black Box Warning"

- Risperdal (risperidone)
- Zyprexa (olanzapine)
- Seroquel (quetiapine)
- Haldol (haloperidol)

# Medications to AVOID with memory loss\*\*

# <u>Tricyclic Antidepressants</u> - Amitriptyline (Elavil) - Nortriptyline (Pamelor) Bladder Medications - Oxybutynin (Ditropan) - Tolterodine (Detrol)

Nortriptyline (Pamelor)Clomipramine (Anafranil)

- Doxepin (Sinequan) Allergy medications

- Imipramine (Tofranil) - Benadryl

- Desipramine (Norpramin) - Chlor-Trimeton

- Protriptyline (Vivactil)

Anti-diarrhea Medications
- Imodium
- Lomotil
- Excedrin PM

Pain Medications (Analgesics)
- Darvocet

Anti-Anxiety
- Valium

- Percocet - Xanax

- Vicodin

<sup>\*\*</sup>Some medications have side-effects or can interact negatively with other medications. This can add to the symptoms you are experiencing. Do not stop medications on your own. Please consult with your Primary Care Provider to review your medications, regarding possible drug interactions or adjustments to your medication.



# 10 Signs of Memory Impairment

- 1. **Memory loss that disrupts daily life**: Asking the same question or repeating the same story over and over again. Forgetting information just learned or losing track of important dates, names and places. Relying heavily on memory aids like Post-it notes or reminders on your smartphone.
- 2. **Difficulty planning or solving problems**: Difficulty concentrating on detailed tasks, especially involving numbers; for example, keeping track of bills and balancing a checkbook.
- 3. **Forgetting how to do familiar tasks**: Forgetting how to do activities that were previously routine, such as cooking, making repairs, or playing cards.
- 4. **Confusion with dates, time or place**: Distorted perception of dates, time or place. Becoming disoriented or feeling lost in familiar places.
- 5. **Trouble with spatial relationships**: Difficulty reading words on a page, judging distances, telling colors apart.
- 6. **New problems with words in speaking or writing**: Trouble finding the right word or calling things by the wrong name. Conversations can be a struggle and difficult to follow.
- 7. **Misplacing objects and the inability to retrace steps**: Finding objects in unusual places, like a watch in the refrigerator. Misplacing things and inability to retrace steps; accusing people of taking things.
- 8. **Altered decision making; poor judgement** or relying on someone else, such as a spouse to make decisions or answer questions. Making poor decisions, such as giving away money inappropriately. Less attention to grooming.
- 9. **Withdrawal from work or social situations**: difficulty initiating activities and participating in social interactions, watching television or sleeping more; lacking motivation. Scaling back on work projects or becoming less involved in favorite hobbies.
- 10. **Mood swings and changes in personality**: Getting upset more easily, feeling depressed, scared or anxious. Being suspicious of people.



# **Communication Techniques**

- 1. They will feel your feelings before they hear your words
- 2. Use short, clear sentences
- 3. Repeat instructions or sentences exactly the same way
- 4. Allow plenty of time for comprehension, repeat as often as needed
- 5. Don't remind someone they forgot something or test their memory
- 6. Agree with them or distract them to a different subject or activity
- 7. Accept the blame when something's wrong (even if it's fantasy)
- 8. Use simple positive instructions ("Please do this")
- 9. Limit Choices, avoid open ended questions
- 10. Leave the room, if necessary, to avoid confrontations
- 11. Respond to the feelings rather than the words
- 12. Remember that you are communicating with an adult:
  - a. Address the person directly
  - b. Avoid "baby talk"
- 13. Practice 100% forgiveness. Memory loss progresses daily.
- 14. Be patient, cheerful and reassuring. Go with the flow. Have a sense of humor.



# **Managing Behaviors**

- Rule out any physical/medical conditions that could trigger a behavior
- Sun downing: agitation or behaviors that occur in the late afternoon/evening
- Coping with changes is hard for someone with Alzheimer's. Try to keep a routine, such as bathing, dressing, and eating at the same time each day.
- Build quiet times into the day, along with activities.
- "engage their senses" by finding activities that stimulate mental, physical, social interactions
- Assess the environment. Reduce noise, clutter, or the number of people in the room.

## Role of Kaiser Permanente

Primary Care 800-290-5000 Neurology Social Worker 619-516-6584

Home Health Care619-641-4663Psychiatry: self-referral877-496-0450Palliative Care (Outpatient, Home Based and Inpatient)

Hospice

**Skilled Care**: a type of intermediate care in which the patient or resident needs more assistance than usual, generally from licensed nursing personnel and certified nursing assistants

**Custodial Care**: nonmedical assistance -- either at home or in a nursing or assisted-living facility -- with the activities of daily life (such as bathing, eating, dressing, using the toilet) for someone who's unable to fully perform those activities without help.

(Not covered by KP or Medicare, resources available under Medi-Cal)

## Types of Custodial Care available

- Day Activities/Outings
- Adult Day Center
- Residential Care (Assisted Living Facility or Board and Care)
- In Home Care
- Respite Care



# **OTHER**

- Have a discussion with your loved one about goals of care going forward
  - o What does quality of life look like to you?
  - o Complete or update Advance Healthcare Directive
    - o Provide a copy to Kaiser to be scanned into patient's chart
  - o Talk with MD about POLST form (Physicians Order for Life Sustaining Treatment)

# Finances/Legal

- o Establish Power of Attorney for medical and financial care
- o Look into other benefits they may have or qualify for
  - Long Term Care insurance, VA benefits, Medi-Cal
- o Elder Law Attorneys are available for consultation

## Driving

- Caregivers should watch for warning signs or unsafe driving
  - Unable to locate familiar places, do not observe traffic signs, makes poor or slow decisions in traffic
- Be sympathetic as you address the topic because retiring from driving, and the perceived loss of independence is difficult for many
- o Visit the Alzheimer's Association® Dementia and Driving Resource Center
  - alz.org/driving
- Create transportation alternatives to remain active and continue activities

## Safety in the home

- o Medical Alert or Take Me Home program
- o Assess your home. Look at your home through the eyes of a person with dementia.
- Lock or disguise hazardous areas.
- o Be prepared for emergencies.
  - o Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals and poison control helplines.
- O Make sure safety devices are in working order. (fire extinguishers, smoke detectors and carbon monoxide detectors)
- o Install locks out of sight. Keep an extra set of keys hidden for easy access.
- Keep walkways well-lit. Add extra lights to prevent accidents and reduce disorientation
- o Remove and disable guns or other weapons.
- o Place medications in a locked drawer or cabinet.
  - o To help ensure that medications are taken safely, use a pill box organizer or keep a daily list and check off each medication as it is taken.
- o Remove tripping hazards. Keep floors and other surfaces clutter-free.



# **Caregiver Support**

Caring for a person with Alzheimer's takes a lot of time and effort. Sometimes, you may feel discouraged, sad, lonely, frustrated, confused, or angry. These feelings are normal.

# Recognize the signs of caregiver stress

- Trouble focusing Difficulty making decisions Change in sleeping habits
  - Feeling overwhelmed
     Feeling irritable
     Becoming isolated
  - Consuming pills, alcohol or caffeine in excess Withdrawing from friends
- Feeling hopeless of helpless
   Becoming emotionally or physically exhausted

#### Develop A Care Plan

- Manage one stressor at a time
- Ask for help and accept it
- Develop coping strategies or self-care routine (exercise, meditation, spiritual care)
- Develop a support system (support groups, friends, family, hired assistance)

## A Caregiver's Bill of Rights

- I have the right to take care of myself. This is not an act of selfishness. It will enable me to take better care of my loved one.
- I have the right to seek help, even though others may object. I recognize the limits of my own endurances and strength
- I have the right to maintain aspects of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

Information for this class was obtained from Alzheimer's San Diego, National Institute on Aging, Southern Caregiver Resource Center, Kaiser Permanente, Aging and Independent Services