



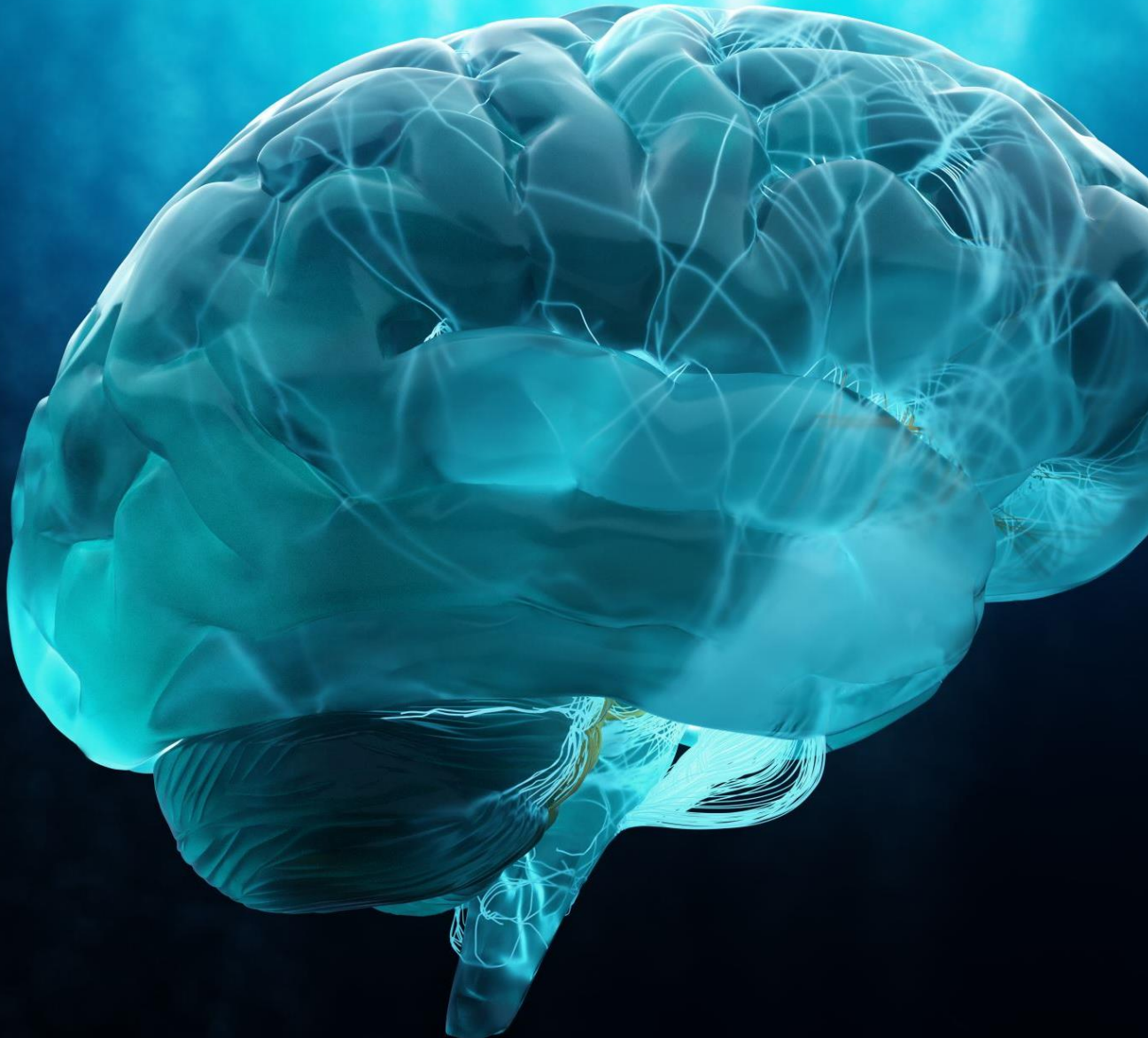
DEMENTIA CARE TRAINING

UNDERSTANDING DEMENTIA
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LEARNING OBJECTIVES

- DEFINE THE DIFFERENT TYPES OF DEMENTIA
- DESCRIBE BEHAVIOR & COMMUNICATION CHALLENGES IN DEMENTIA PATIENTS
- UNDERSTANDING CAREGIVER STRESS
- IDENTIFY AND REPORT POTENTIAL ABUSE
- DEVELOP STRONGER CARE PLANS FOR DEMENTIA MEMBERS



WHAT IS DEMENTIA?

- Dementia is caused by damage to brain cells. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior and feelings can be affected
- Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life.
- Disorders grouped under the general term “dementia” are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings and relationships.



UNDERSTANDING NORMAL AGING

- SLOWER THINKING; BUT INTELLIGENCE REMAINS THE SAME
- INCREASED DIFFICULTY IN FINDING THE RIGHT WORD TO DESCRIBE OR FINISH A SENTENCE
- SLOW, MILD DECREASE IN SHORT-TERM MEMORY WHILE LONG TERM MEMORY REMAINS INTACT
- CHANGES IN SENSES
- DECREASE IN ATTENTION SPAN AND DIFFICULTY PAYING ATTENTION
- SLOWER PROCESSING OF INFORMATION

EARLY SYMPTOMS OF DEMENTIA

Signs of dementia can vary greatly. Dementia is defined as a “significant deterioration in two or more areas of cognitive function that is severe enough to interfere with a person’s ability to perform everyday activities.” Examples include problems with:

Short-term memory.

Keeping track of a purse or wallet.

Paying bills.

Planning and preparing meals.

Remembering appointments.

Traveling out of the neighborhood.

Many conditions are progressive, which means that the signs of dementia start out slowly and gradually get worse

DIAGNOSING DEMENTIA

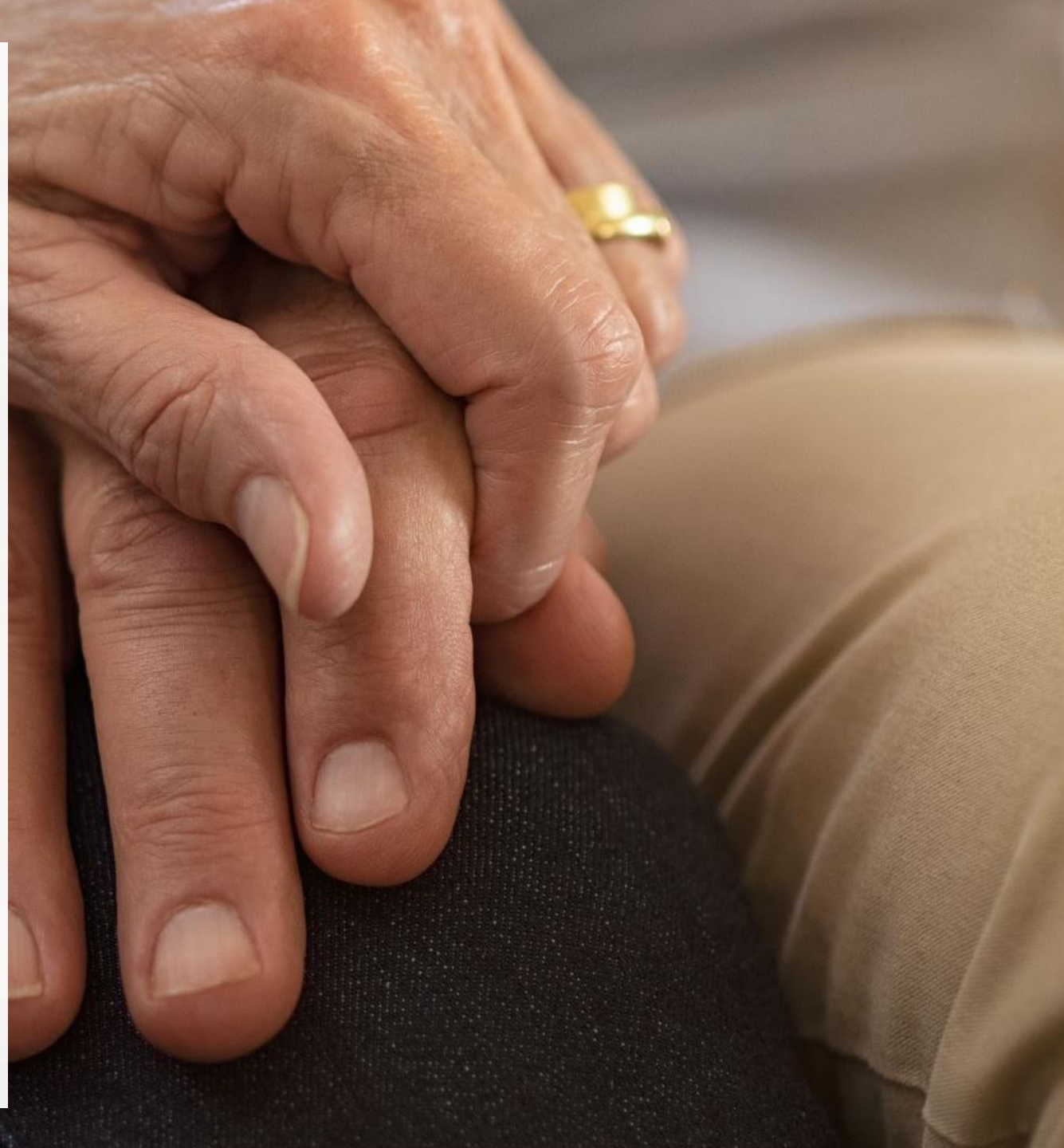
DIAGNOSIS OF DEMENTIA REQUIRES IMPAIRMENT OF TWO OR MORE CORE MENTAL FUNCTIONS:

- MEMORY
- LANGUAGE SKILLS
- VISUAL PERCEPTION
- ABILITY TO FOCUS AND PAY AFFECTION
- ABILITY TO REASON AND SOLVE PROBLEMS

THE LOSS OF THE BRAIN FUNCTION HAS TO BE SEVERE ENOUGH THAT A PERSON HAS DIFFICULTY PERFORMING NORMAL EVERYDAY TASKS

TYPES OF DEMENTIAS

- VASCULAR DEMENTIA
- MIXED DEMENTIA
- DEMENTIA WITH LEWY BODIES
- FRONTOTEMPORAL DEMENTIA
- ALZHEIMER'S DISEASE
- REVERSIBLE DEMENTIAS





VASCULAR DEMENTIA

- Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain, depriving them of oxygen and nutrients.
- In vascular dementia, changes in thinking skills sometimes occur suddenly after a stroke, which blocks major blood vessels in the brain. Thinking difficulties may also begin as mild changes that gradually worsen as a result of multiple minor strokes or another condition that affects smaller blood vessels, leading to widespread damage.
- About 5% to 10% of people with dementia have vascular dementia alone
- The impact of vascular conditions on thinking skills varies widely, depending on the severity of the blood vessel damage and the part of the brain it affects. Memory loss may or may not be a significant symptom depending on the specific brain areas where blood flow is reduced. Vascular damage that starts in the brain areas that play a key role in storing and retrieving information may cause memory loss that is very similar to Alzheimer's disease.



Symptoms of Vascular Dementia

- Confusion
- Disorientation
- Trouble speaking or understanding speech
- Physical stroke symptoms, such as a sudden headache
- Difficulty walking
- Poor balance
- Numbness or paralysis on one side of the face or the body

MIXED DEMENTIA

Mixed dementia is a condition in which brain changes of more than one cause of dementia occur simultaneously.

In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer's disease coexist with blood vessel problems linked to vascular dementia

Mixed dementia symptoms may vary, depending on the types of brain changes involved and the brain regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of Alzheimer's or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present.



DEMENTIA WITH LEWY BODIES

- type of progressive dementia that leads to a decline in thinking, reasoning and independent function. Its features may include spontaneous changes in attention and alertness, recurrent visual hallucinations, REM sleep behavior disorder, and slow movement, tremors or rigidity.
- Alpha-synuclein protein, the chief component of Lewy bodies, is found widely in the brain, but its normal function isn't yet known.

Lewy bodies may also be found in other types of dementia, including [Alzheimer's disease dementia](#), and are a primary brain abnormality in [Parkinson's disease dementia](#). Many people with Parkinson's eventually develop problems with thinking and reasoning, and many people with DLB experience movement symptoms like hunched posture, rigid muscles, a shuffling walk and trouble initiating movement.



SYMPTOMS OF DLB

- Core symptoms of dementia with Lewy bodies include:
 - Changes in thinking and reasoning.
 - Fluctuating cognition that is delirium-like.
 - Recurrent well-formed visual hallucinations.
 - REM sleep behavior disorder that involves acting out dreams.
 - Spontaneous parkinsonism with slowness of movement, rest tremor, or rigidity.
- Other symptoms may include:
 - Trouble interpreting visual information.
 - Malfunctions of the "automatic" (autonomic) nervous system, which controls automatic functions of the body, such as sweating, blood pressure, heart rate, digestion and sexual response.
 - Memory loss that may be significant, but less prominent than in Alzheimer's.

FRONTOTEMPORAL DEMENTIA

- Frontotemporal dementia (FTD) or frontotemporal degeneration refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes (the areas behind your forehead) or its temporal lobes (the regions behind your ears).
- The nerve cell damage caused by frontotemporal dementia leads to loss of function in these brain regions, which variably cause deterioration in behavior, personality and/or difficulty with producing or comprehending language.
- There are a number of different diseases that cause frontotemporal degeneration. The two most prominent are 1) a group of brain disorders involving the protein tau and 2) a group of brain disorders involving the protein called TDP43. For reasons that are not yet known, these two groups have a preference for the frontal and temporal lobes that cause dementia.

TYPES OF FRONTOTEMPORAL DEMENTIA

Behavioral variant frontotemporal dementia
(bvFTD)



PRIMARY PROGRESSIVE APHASIA
(PPA)



DISTURBANCES OF MOTOR





BEHAVIORAL VARIANT FRONTOTEMPORAL DEMENTIA (BVFTD)

- Behavioral variant frontotemporal dementia (bvFTD), sometimes also called behavior variant FTD, is characterized by prominent changes in personality and behavior that often occur in people in their 50s and 60s, but can develop as early as their 20s or as late as their 80s. In behavioral variant frontotemporal dementia, the nerve cell loss is most prominent in areas that control conduct, judgment, empathy and foresight, among other abilities.

PRIMARY PROGRESSIVE APHASIA

Primary progressive aphasia (PPA) is the second major form of frontotemporal degeneration that affects language skills, speaking, writing and comprehension. PPA normally comes on in midlife, before age 65, but can occur in late life also. The two most distinctive forms of PPA have somewhat different symptoms:

In semantic variant of PPA, individuals lose the ability to understand or formulate words in a spoken sentence.

In nonfluent/agrammatic variant of PPA, a person's speaking is very hesitant, labored or ungrammatical.

DISTURBANCES OF MOTOR MOVEMENT

- Disturbances of motor (movement or muscle) function include three disorders that are a part of the frontotemporal degeneration spectrum that produce changes in muscle or motor functions with or without behavior (bvFTD) or language (PPA) problems:
 - Amyotrophic lateral sclerosis (ALS), which causes muscle weakness or wasting. ALS is a motor neuron disease also known as Lou Gehrig's disease.
 - Corticobasal syndrome, which causes arms and legs to become uncoordinated or stiff.
 - Progressive supranuclear palsy (PSP), which causes muscle stiffness, difficulty walking and changes in posture. It also affects eye movements. Symptoms of PSP may resemble symptoms of Parkinson's disease. However, in PSP tremor is less common and speech and language problems tend to develop earlier.

ALZHEIMER'S DISEASE

- Alzheimer's is a type of dementia that affects memory, thinking and behavior. Symptoms eventually grow severe enough to interfere with daily tasks.
- Alzheimer's is the most common cause of dementia, a general term for memory loss and other cognitive abilities serious enough to interfere with daily life. Alzheimer's disease accounts for 60-80% of dementia cases.
- Alzheimer's is not a normal part of aging.
- Alzheimer's worsens with time.
- Alzheimer's has no cure



EARLY SIGNS OF ALZHEIMER'S

MEMORY LOSS
THAT DISRUPTS
DAILY LIFE

CHALLENGES IN
PLANNING OR
SOLVING
PROBLEMS

DIFFICULTY
COMPLETING
FAMILIAR TASKS

CONFUSION WITH
TIME AND/OR
PLACE

TROUBLE
UNDERSTANDING
VISUAL IMAGES &
SPATIAL
RELATIONSHIPS

NEW PROBLEMS
WITH WORDS IN
SPEAKING OR
WRITING

MISPLACING
THINGS & LOSING
THE ABILITY TO
RETRACE STEPS

DECREASED OR
POOR JUDGEMENT

WITHDRAWAL
FROM WORK OR
SOCIAL ACTIVITIES

CHANGES IN
MOOD &
PERSONALITY

DISEASE PROGRESSION

EARLY STAGE:

- Insight into disease; depression; misplacing things; getting lost; many losses being experienced; ability to make decisions/plan ahead; problems with memory and concentration

MIDDLE STAGE:

- Difficulty with communication; behavioral symptoms; obvious memory and thinking problems

LATE STAGE:

- Functional decline; ADL assistance needed; unable to have conversation; trouble swallowing; loss of bladder control



REVERSIBLE DEMENTIA

- DEMENTIA CAN BE REVERSIBLE IF IT IS TEMPORARILY CAUSED BY SOME OF THE FOLLOWING:
- DEPRESSION, DELIRIUM
- METABOLIC DISORDERS
- EYE AND EAR IMPAIRMENTS
- NUTRITIONAL (ie: B12 DEFICIENCY)
- TUMORS
- INFECTIONS
- ALCOHOL, DURGS, MEDICAL INTERACTIONS



COMMUNICATION AND BEHAVIOR



COMMUNICATION CHANGES

- Changes in the brain cause a change in the way people communicate with other and their needs.
- Suffering from dementia impairs an individual's ability to effectively communicate which will lead to certain behaviors that the individual will display in attempts to communicate their need or feeling.
- The most common changes in communication are:
 - difficulty in finding a word – a related word might be given instead of one they cannot remember
 - the use of speech that does not make sense
 - an inability to understand what you are saying or the ability to only grasp a part of what you are saying
 - writing and reading skills that have deteriorated
 - loss of the normal social conventions of conversation – an increasing tendency to interrupt, ignore a speaker or fail to respond when spoken to
 - difficulty in expressing emotions appropriately.



BEHAVIORAL CHANGES

- IT IS VERY IMPORTANT TO REMEMBER BEHAVIORAL SYMPTOMS ARE NOT:
 - INTENTIONAL
 - THE PATIENT TRYING TO BE DIFFICULT
 - DUE TO POOR LISTENING
- CHANGES IN BEHAVIOR WILL CONTINUE TO INCREASE AS THE DEMENTIA/DISEASE PROGRESSES AND CAN BE MANIFESTED AS SUCH:
 - ANGER
 - YELLING
 - FRUSTRATION
 - DEPRESSION
 - INCREASE IN AGGRESSION AS FAMILIAR FACES MAY NOW BE STRANGE AND THE INDIVIDUAL MAY FEEL A SENSE OF FEAR

As the disease begins to progress an individual will have more challenging behaviors which will then lead to increased caregiver stress and poor coping



Decreased ability of caregiver to use behavioral strategies



Increases more challenging behaviors

IMPACTS OF BEHAVIOR CHANGES



Behavioral Changes (Continued)

- Dementia will begin to impact not just the individual's life but the caregivers as well. The risk for a downward spiral is very high:
 - Decreased quality of life
 - Increased functional decline
 - Increased caregiver distress
 - Increased health care utilization/hospitalizations and cost
 - Earlier nursing home placement



COMMUNICATION STRATEGIES

- Components that determine impact of communication :
 - 55% of our communication is body language (postures, gestures, eye contact)
 - 38% is our tone of voice and the feeling attached to it
 - 7% actual word content

As the dementia progresses it is important to keep in mind that communication styles will be key to diminish the frustration and make the individual feel as though they are being heard and understood given their new limitations.



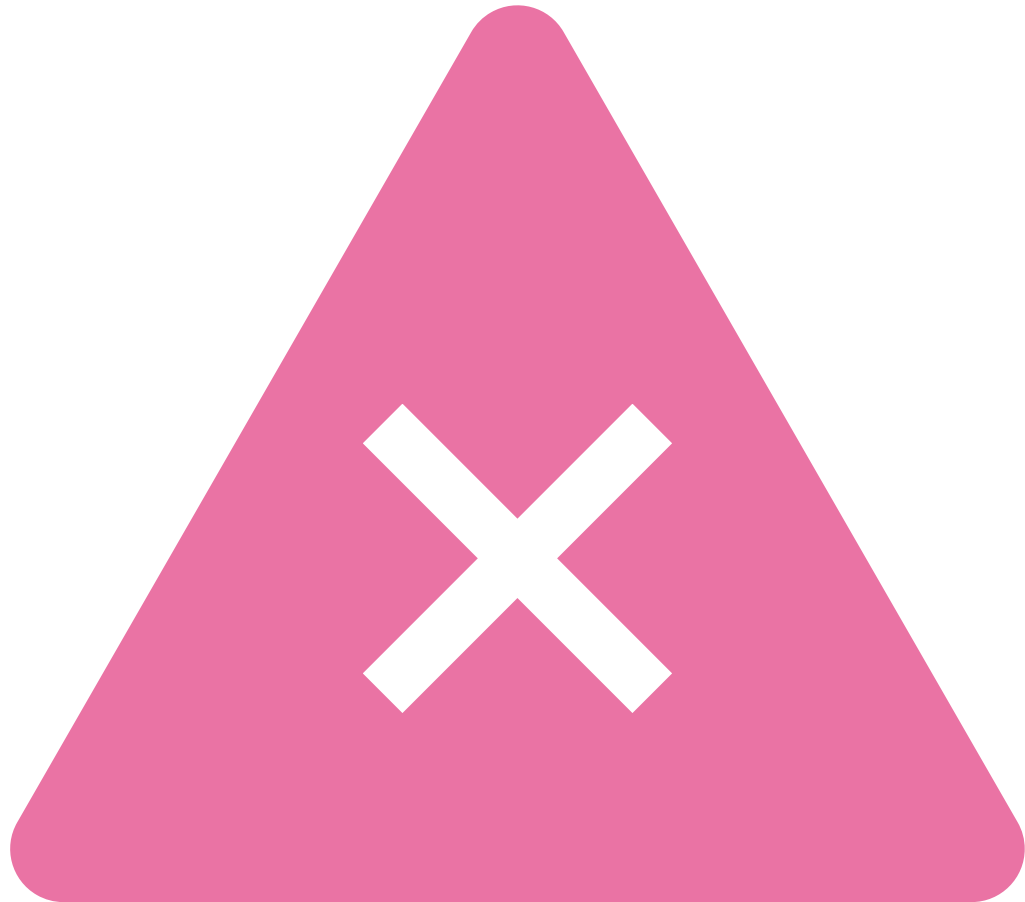
IMPROVING COMMUNICATION

- When communicating with an individual suffering from dementia at any stage it can be very helpful to put yourself in their position by asking yourself questions such as:
 - How would you feel if you were cold and did not have a way to tell someone you wanted a jacket?
 - How would you feel if you were being forced to take a shower in a cold bathroom when you prefer a hot steamy bath?
 - How would you feel if you looked in the mirror and did not recognize yourself and thought that there was a stranger in the room?
 - How would it feel to wake up every morning not knowing where you are, who you are, how old you are, who your family is?
 - How would you attempt to explain what's going on in your head without having the ability to do so?



ADJUST YOUR APPROACH

- A person suffering from dementia does not have the ability to adjust their communication given their cognitive deficit so it is important to remember that you have the ability to change your approach. Ways you can change your approach are:
 - Find New Ways to communicate and connect:
 - Words, Movement, How we approach someone
 - Facial expressions
 - Tone of Voice
 - Touch
 - Give short, one sentence explanations
 - Allow plenty of time for comprehension and response.. and then triple the time
 - Repeat instructions or sentences exactly the same way



THINGS TO AVOID

- Don't argue-arguing with a person that is already confused will only increase the frustration
- Don't reason-attempting to reason with a person with diminished cognitive abilities is a no-win situation
- Don't confront- being aware of the individual's state of mind is important to allow you time to step back and not become argumentative
- Don't remind them they forgot something and question their memory abilities
- Don't insist-doing so will only lead to an argument and increase the frustration.



IDENTIFYING & REPORTING ABUSE

ELDER ABUSE

As many as 1 in 10 older adults, and 1 in 2 people with dementia, are victims of elder abuse.

For every reported case of elder abuse, there are 23 that go unreported.

70-90% of perpetrators of elder abuse are family members, loved ones or caregivers.


Reporting helps link families to needed services

Victims of elder abuse are two times more likely to be hospitalized than other seniors.

AS A REMINDER WE ARE ALL MANDATED REPORTERS AND BY LAW MUST REPORT ANY SUSPICION OF ABUSE

WHAT MUST BE REPORTED?

Abandonment: when an individual is left alone and has some physical, mental or emotional disability that requires them to be supervised or assisted in their daily ADL's.



Isolation: Isolating an individual from family/ friends to continue to hide the abuse



Neglect: defined as an individual's needs being neglected or not addressed



Financial Abuse: when an individual's finances are being mishandled or utilized in ways that are not authorized/beneficial to the individual.



Self Neglect: deficits in physical self-care; medical care, health and safety hazards and/or malnutrition



SUPPORTING
CAREGIVERS



WHAT DO CAREGIVERS DO?

- Manage co-existing conditions/treatment
- Medication Management
- Wound Care
- Manage behavioral symptoms
- Appointments
- Transportation
- Hygiene
- Meal Prep
- Housekeeping
- Home Safety
- Decision-Making
- Supervision
- Socialization



Dementia Caregivers

- Caregiving needs and job becomes more demanding as disease progresses.
- Caregivers need to learn a whole new language (behavior & communication)
- Person with dementia cannot change (only caregiver can adapt)
- Physical, mental and emotional demands become greater as the individual continues to decline
- Caregivers can begin to exhibit the following:
 - Depression, social isolation
 - Anxiety; Fatigue; Burnout
 - Emotional Stress

INDICATORS OF CAREGIVER STRESS

Denial

Anger

Social
Withdrawal

Anxiety

Depression

Exhaustion

Sleeplessness

Irritability

Lack of
concentration

Health
Problems

ASSISTANCE AND ENCOURAGEMENT

Educate and encourage	Educate and encourage the importance of stress management skills
Promote	Promote Caregiver Support Groups both in person or virtually
Encourage	Encourage staying on top of their own health and making it a priority to decrease burnout
Address	Address family conflict
Discuss	Discuss alternatives for caregiving options
Revisit	Revisit future alternatives to home care by encouraging long term planning

DEMENTIA CARE MANAGEMENT



WHAT MAKES DEMENTIA CARE MANAGEMENT UNIQUE?

LOSS OF INSIGHT &
DECISION -MAKING
CAPACITY

COGNITIVE &
FUNCTIONAL
LIMITATIONS

LACK OF DIAGNOSIS

CAREGIVER
INTEGRATED INTO
CARE
COORDINATION &
CARE PLANS

24/7 CAREGIVING

BEHAVIORAL
SYMPTOMS

CREATIVE
APPROACHES MAY
BE NEEDED

CAREGIVERS MAY
NEED ADDITIONAL
TRAINING AND
INCREASED
SUPPORT

CO-EXISTING
CONDITIONS CAN
BE CHALLENGING
TO MANAGE

DIFFICULTY MONITORING & MANAGING CO-EXISTING CONDITIONS



Loss of cognitive ability to understand multiple conditions and disease management



Difficulty attending follow-up medical appointments/visits.



Less ability to express symptoms, leading to delays in seeking treatment



Caregiver education can be challenging as they must learn techniques to manage co-existing conditions while understanding the disease progression.



Care managers must work to understand; address and constantly come up with different ways of managing co-existing conditions given a member's current cognitive state

Examples of Managing Co-Existing Conditions

Congestive Heart Failure	Challenge of Dementia	Potential Adaptation Strategies
Monitoring Weight	Person refuses to go onto scale; Person is unsteady when going onto scale	Try encouraging caregiver to weigh person when they are more relaxed; Make weighing a daily activity
Taking Medication	Cannot rely on patient to take medication; Patient unable to differentiate between medications	Caregiver administers medication; Utilizing a Pill Box; Setting up alarms to remind a patient to take medication

Creating Care Plans

- Dementia can lead to challenging behaviors:
 - Sleep disturbances
 - Sadness and/or depression
 - Combativeness
 - Hallucinations
 - Sundowning
 - Suspiciousness and Paranoia
 - Screaming and making noises
 - Resisting Bathing or showering
 - Difficulty with dressing and grooming
 - Difficulty using the bathroom
 - Poor Medication Management
 - Getting Lost

MAKE REFERRALS WHEN APPROPRIATE

1

Clarify service need

2

Be specific

3

Carefully match caregiver to agency (consider language, cost, geography, culture)

4

Be proactive and anticipatory

5

Go the extra mile for families

6

Encourage supportive services for caregivers to diminish the risk of burnout.

BETTER OUTCOMES

Adjusting plans of care and approach with a person suffering from dementia can lead to the following:

Ensure social determinants of health are met

Reduce caregiver stress and burnout

Improve quality of life

Reduce hospitalizations/readmission

Delay/ Prevent institutionalization and keep patient home



Understanding dementia and the effects it has on an individual/caregiver will only help to ensure quality care is being provided to all our members and all their needs are being appropriately addressed.



Living with Dementia

- This video put together by the Alzheimer's Association gives us a small view into a person living with dementia
- https://youtu.be/q_sWiwI3yP0

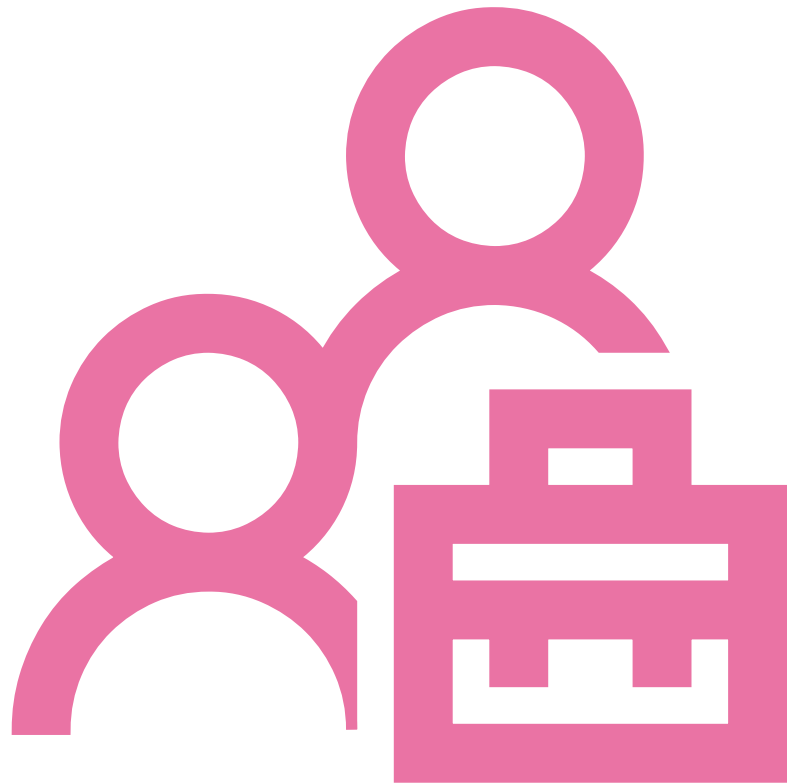


COMMUNITY RESOURCES



ALZHEIMER'S ASSOCIATION

- <https://www.alz.org>
- Offers a lot of resources for individual's suffering with dementia, caregivers and providers
- Variety of supportive materials
- Resources for local support for families
- Information on disease progression and ways to navigate through the different stages



Department of Aging

- <https://aging.ca.gov>
- Provides Resources for all different types of illnesses
- Resources/tools on how to navigate and access different supportive services
- Breaks down resources for all counties across California
- Resources for caregiving and agencies that will provide services to try to promote independence at home



Adult Day Care Centers

- Adult Day Care Centers are facilities that promote healthy wellbeing
- Provide therapeutic services that try to assist with cognitive deficits
- Provide a respite for caregivers to relax and go about their day without worrying about caring for the patient
- Promote socialization to decrease isolation
- Each city has their own list of adult day care centers
- https://aging.ca.gov/Care_Options/Adult_Day_Services_Programs/



Poem by Anonymous

A memory may fade day by day, but in my heart they will always stay. I'm still the same person when you look into my eyes, it's just this illness keeping me in disguise. When you touch me by the hand, please try and understand, that I'm trying to be myself again and making my stand. I may forget a word or two as time goes by, but never forget that I still love you and I'll show as I will try. If I forget your name, please don't think really have forgotten you, because love never forgets or dies, it lives on by the people who love you. Remember me who I once was and help me to remember too, I'll try my best to still be there for you. Don't forget me because what I need you to do, is to keep my memories of who I once was alive through you. Alzheimer's may have taken a lot from me, but I promise with all my love, I will always love you and Alzheimer's can't take that away, even the good Lord knows that from up above!