Orange County

In~Home Supportive Services

Public Authority

PARTNERSHIP FOR SUCCESSFUL PROVIDERS

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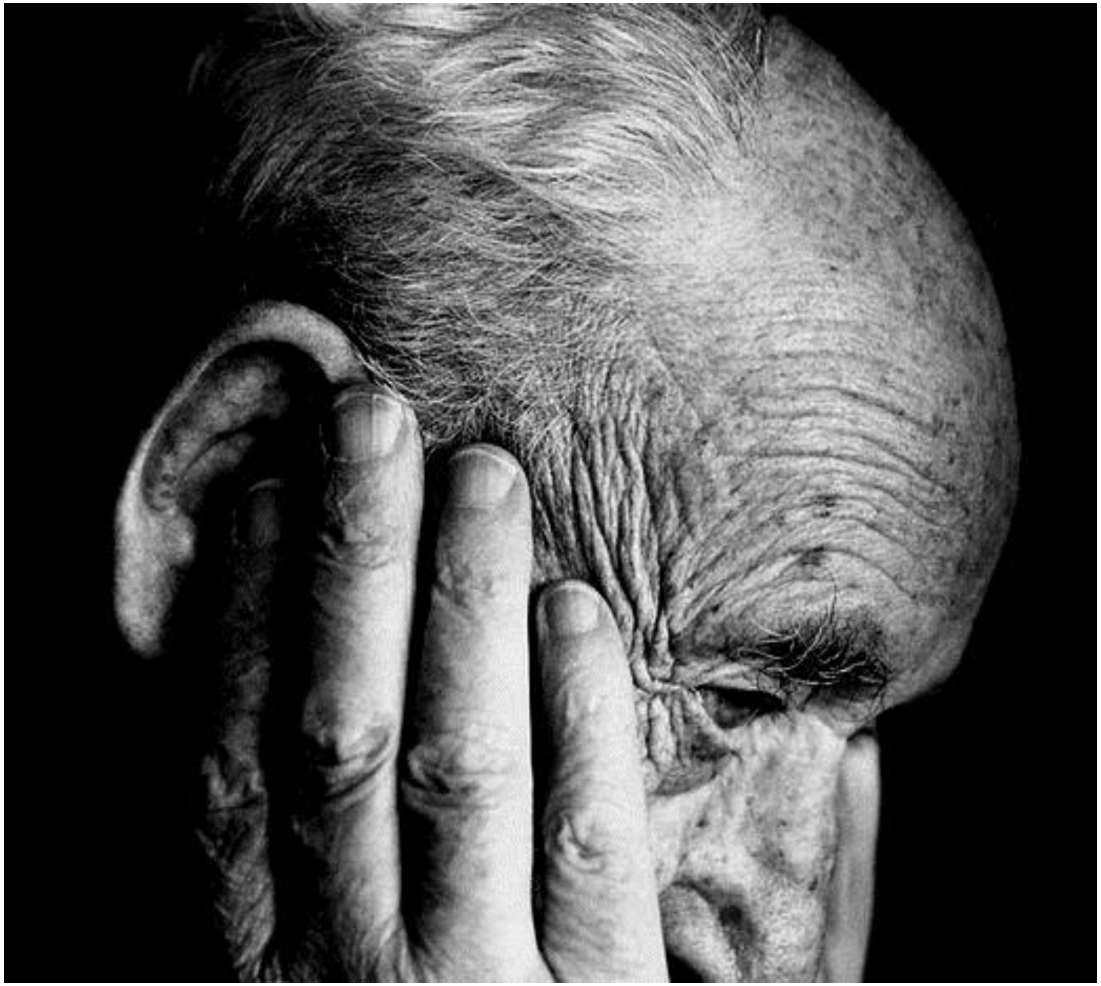


UNDERSTANDING ALZHEIMER'S DISEASE

Working hand in hand with the community to serve IHSS Consumers so they may remain safe and independent in their own home.

Items to be discussed

- Statistics
- Objective of the Class
- DVD
- What is Alzheimer's Disease
- How Does the Person Change
- Common Behaviors
- Stages of Alzheimer's Disease
- Challenges of Communication
- Caregiver's Role and Responsibilities
- Important Reminders
- Resources

Statistics of Alzheimer's

Alzheimer's is the most common form of Dementia.

It accounts for 60-80 percent of Dementia cases.

It is estimated that more than 5.0 million people in the United States are currently living with symptoms of Alzheimer's.

Studies report that by 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to a projected 13.8 million. Previous estimates suggest that this number may be as high as 16 million.

Objective

- To gain a better understanding of Alzheimer’s Disease
    - What is Alzheimer’s
    - Behaviors
    - Warning signs
    - Stages
- To learn the principles and practical techniques of communication
- To gain an understanding of how to address challenging behaviors
- To learn what Providers can do to encourage a positive environment for the client and the Provider

DVD

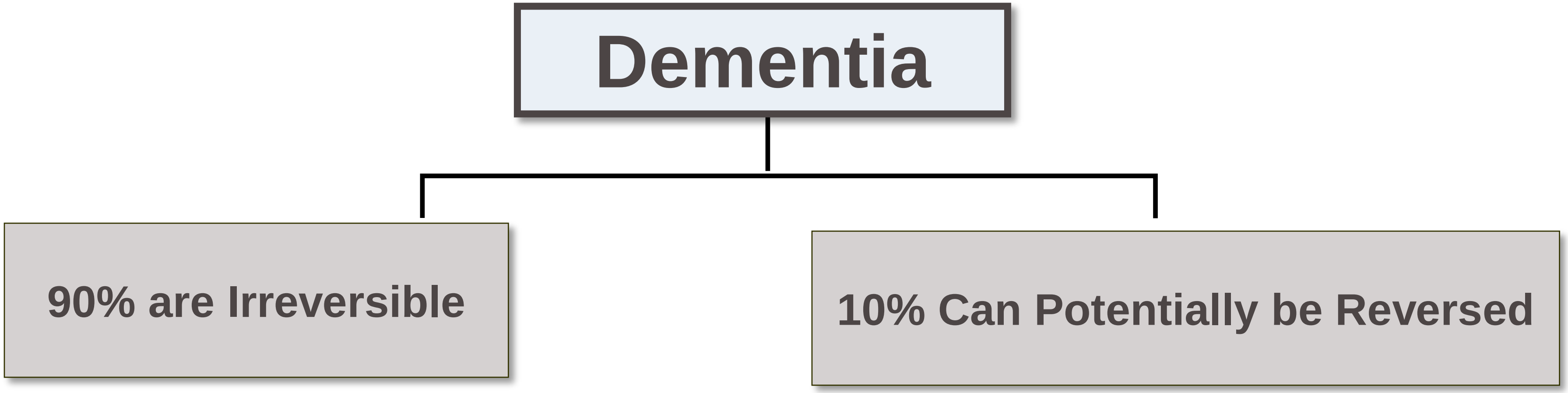
DVD

What is Alzheimer’s

Alzheimer’s is the most common form of Dementia.

- Dementia is a loss of brain function that occurs with certain diseases. It affects memory, thinking, language, judgment, and behavior.
- Dementia a slow progressing disease that damages the brain.
- Dementia itself is NOT a disease or a specific diagnosis.
- Dementia is NOT part of the normal aging process.

Alzheimer's Cannot be Reversed



Dementia

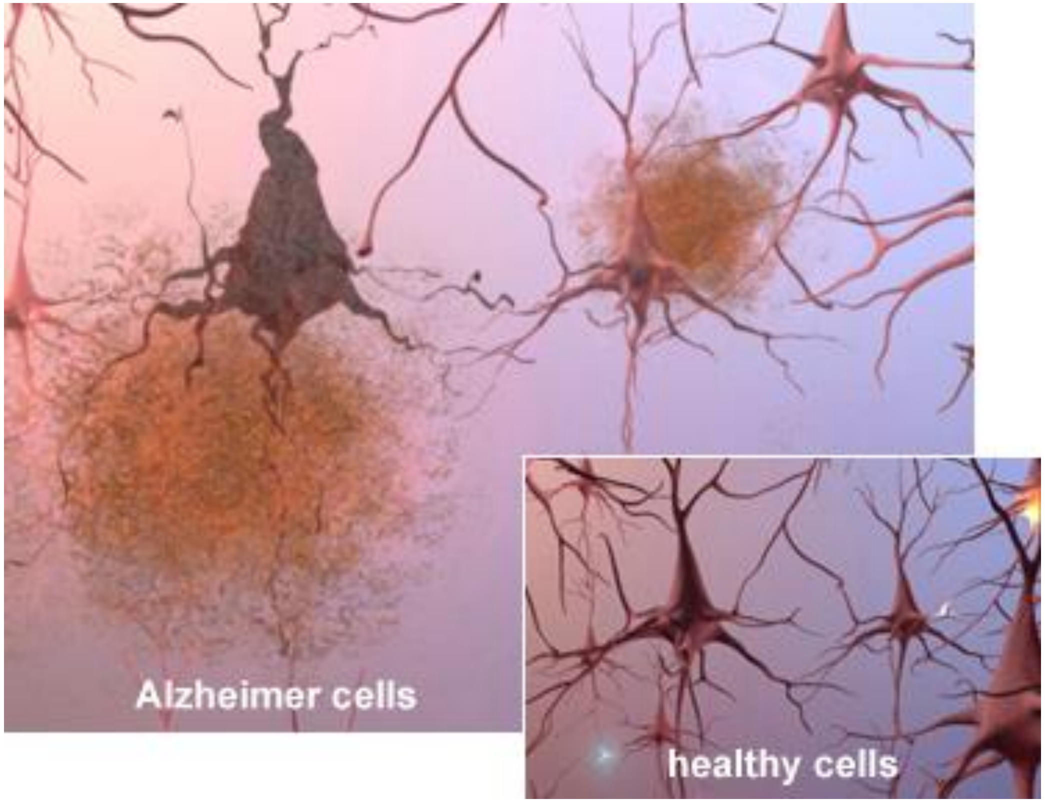
90% are Irreversible

10% Can Potentially be Reversed

- **Alzheimer's Disease**
- Lewy Body Dementia
- Frontal Temporal Dementia
- Vascular Dementia
- Alcohol Related

- Depression
- Metabolic Problems
- Medications: adverse reactions
- Infections
- Brain Tumors
- Sensory Loss
- Nutritional Deficiencies

Alzheimer’s: What does it look like



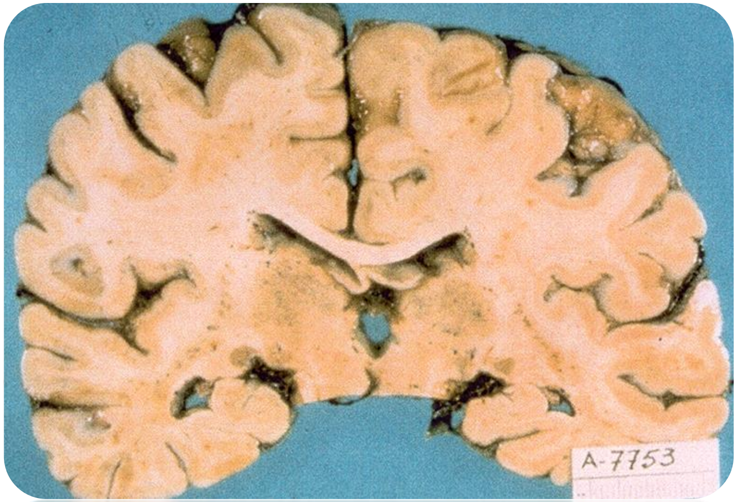
Changes in the brain may start 20 years before symptoms are detected.

Plaques and tangles increase over time and although the average progression of the disease is 8 years, it may last 2 – 20 years.

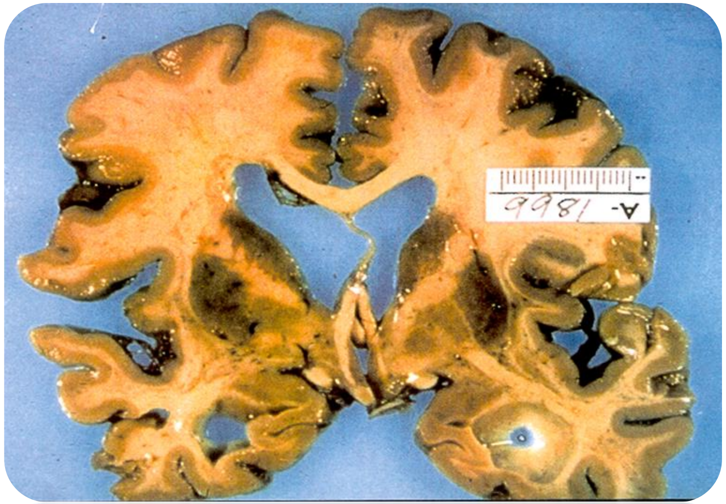
The communication between nerve cells begins to fail and symptoms become noticeable when the brain can no longer compensate for changes in the neurons.

Alzheimer's

Although Alzheimer's gets progressively worse and is ultimately fatal, proper care and support can help most individuals with Alzheimer's live a comfortable life for many years.

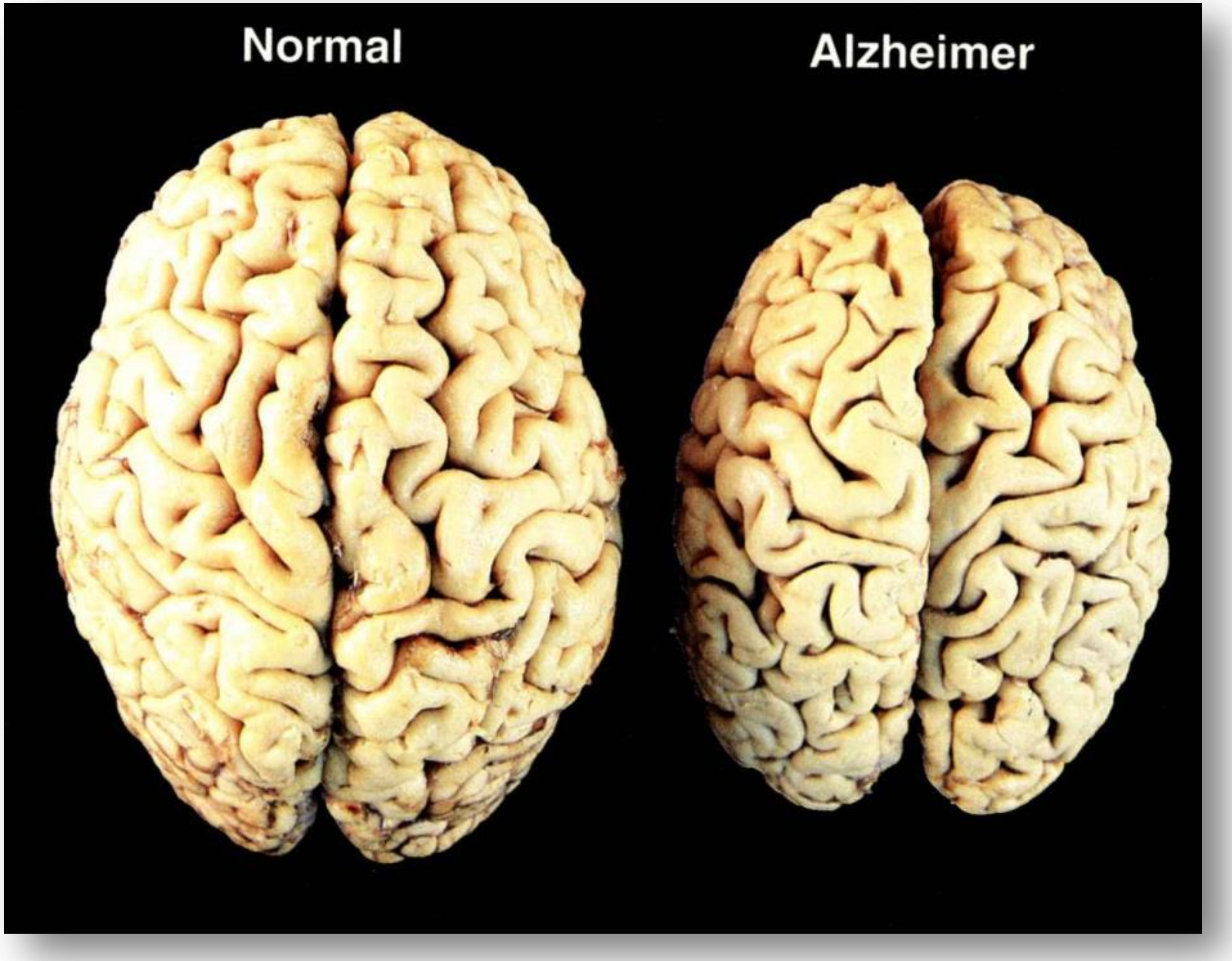


Normal Brain



Alzheimer's Brain

Alzheimer’s: Brain Size



Alzheimer’s: How Does the Person Change

Memory	Forget recently learned information, dates, events; repeat statements/questions; forget individuals who were previously familiar to them
Language / Communication	They may experience difficulty following or joining a conversation; may stop in the middle of a conversation and not know how to continue; have problems finding the right word; call a watch a ‘hand-clock”
Executive Functions	Difficulty with decision making, reasoning, attention, social behavior, speech, language, completing daily tasks; they lose track of dates, seasons and passage of time; they have difficulty concentrating, following a plan or working with numbers
Visual-Spatial Perception	They have difficulty reading, judging distance and determining color/contrast; may pass a mirror and think there is someone else in the room
Behavior	They may become anxious or aggressive (verbal and physical); wander & get lost; experience confusion, suspicion; can experience hallucinations

Alzheimer’s: Common Behaviors

Aggression:	Aggressive behavior can be verbal (shouting, name calling) or physical (hitting, pushing). Aggressive behavior can occur suddenly. It is important to try to identify the triggers that make the person become angry/upset. Is it medical, is the environment too noisy, are they in pain, etc.
Wander & Get lost:	They often have a purpose or goal. They may try to go home when in actuality they are already at home. They may attempt to recreate a familiar routine, such as going to school or work.
Anxiety/Agitation:	they may become restless and need to move around or pace. They may become upset for many different reasons.
Confusion:	They may not recognize familiar people (including family), places or common items (toothbrush, forks, pens, etc.).

Alzheimer's: Common Behaviors

Hallucinations: Some individuals may see, hear, smell, taste or feel things that are not there. It is important to acknowledge their emotions and occurrence.

- They may see a face of a former friend on a curtain
- They may hear people talking
- If the occurrence is continuous, a doctor must be notified to determine if there is an underlying cause.

Repetition: They may say or do something over and over again, possibly looking for comfort, security and familiarity. The person may also pace or undo what has just been finished. These actions are rarely harmful to the person, but can be stressful for the caregiver

Sundowning Syndrome & Sleep Disturbance: The person may experience periods of increased confusion, anxiety and agitation beginning at dusk and continuing throughout the evening. The causes of this condition are unknown. There are factors that can contribute toward this behavior, such as end-of-day exhaustion or less need for sleep.

Suspicion: Memory loss and confusion may cause the individual to perceive things differently. They can become suspicious of individuals around them and blame them of inappropriate behavior such as theft and infidelity.

Alzheimer's: Common Behaviors

Why do behavioral problems occur?

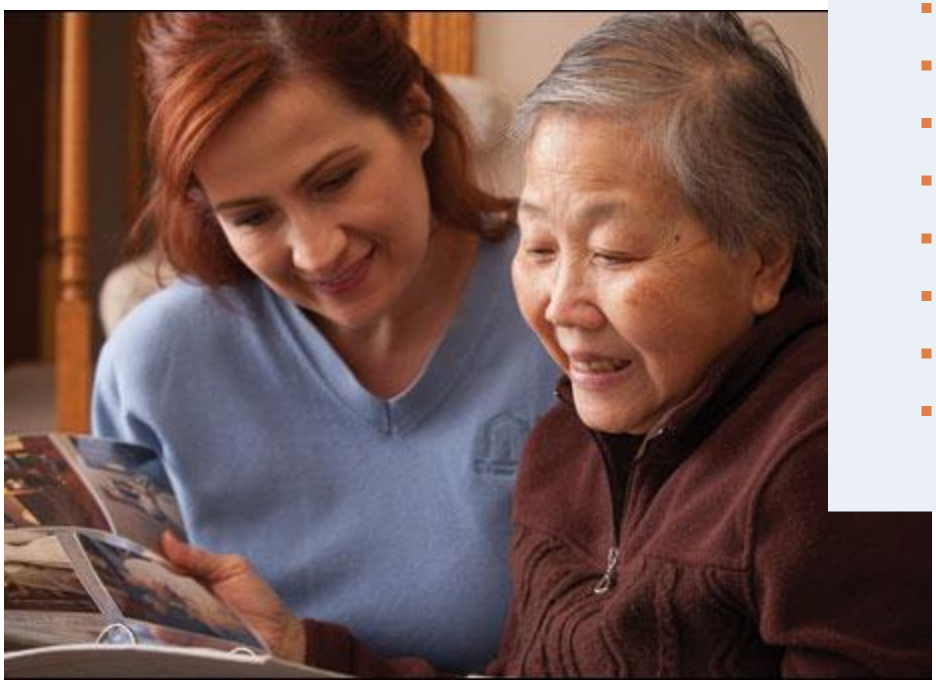
- Breakdown of the brain structure can cause:
  - Mood swings
  - Loss of understanding and logic
  - Uncontrollable repetition of a response, word, phrase
  - Lack of inhibition
  - Difficult and agitated behaviors

- A person with dementia experiences the world differently
  - What they experience and perceive is *REAL* to them
  - The delusions or hallucinations they experience are also very real to them
  - It's important to not try to reason with the individual
    - For example, they may believe they are having a conversation with a loved one from their past (a deceased family member or friend)
- Lack of short term memory, confusion, and fear, among other problems can cause agitation, anger and/or frustration and other behavioral problems

- A decreased ability to recognize their surroundings
  - They may not recognize their home or other locations they previously visited

Alzheimer’s: Common Behaviors

What to consider when addressing the person’s behavior:



- What is the behavior?
- Is the behavior harmful to the individual or others?
- Did something trigger the behavior?
  - What happened before and after?
  - How did you react ?
  - Are they thirsty/hungry ?
  - Do they have to go to the bathroom ?
  - Is it too hot/cold ?
  - Is he/she not feeling well/feeling pain ?
  - Could it be the medication (over medicated) ?
  - Are they feeling overwhelmed ?

Alzheimer’s: Stages 1 & 2

Stages are used to describe how a person’s abilities change as the disease progresses.

Although stages have been identified, it is important to understand that a person can show symptoms of one stage on one day and show symptoms of a previous stages on another –this disease is NOT linear.

Alzheimer’s Disease is unique to each person

Stage 1: No impairment (normal function)

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2: Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer’s disease)

Individuals may feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. These problems are not evident during a medical examination or apparent to friends, family or co-workers.

Alzheimer’s: Stage 3

Stage 3: Mild cognitive decline (mild or early stage)

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview.

- The person is typically in denial that there is a problem
- Difficulty with word- or name-finding
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings
- Difficulty retaining material recently read, recent events and conversations
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

Alzheimer's: Stage 4

Stage 4: Moderate cognitive decline (mild or early-stage)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic
    - Count backward from 100 by 7s
- Decreased capacity to perform complex tasks
    - planning dinner for guests
    - paying bills and managing finances
- Reduced memory of personal history
- They may seem subdued and withdrawn, especially in socially or mentally challenging situations.

Alzheimer’s: Stage 5

Stage 5: Moderately severe cognitive decline (moderate or mid-stage)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential.

- They may be unable to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated, when asked during a medical interview
- Become confused about where they are or about the date, day of the week or season
- Have trouble with less challenging mental arithmetic – counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own names and the name of their spouses or children
- Usually require no assistance with eating or using the toilet

Alzheimer's: Stage 6

Stage 6: Severe cognitive decline (moderately severe or mid-stage)

Memory difficulties continue to become worse, significant personality changes may develop and effected individuals need extensive assistance with activities of daily living.

- Lose most awareness of recent experiences, events, and surroundings
- Recollect their personal histories imperfectly, but can generally recall their own names
- Occasionally forget the name of their spouses or primary caregivers but can generally distinguish familiar from unfamiliar faces
- Need help getting dressed properly
  - without supervision, may put pajamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycles
- Need help with handling details of toileting
  - flushing toilet, wiping and disposing of tissue properly
- Have increasing episodes or urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (believing their caregiver is an imposter); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

Alzheimer’s: Stage 7

Stage 7: Very severe cognitive decline (severe or late-stage)

This is the final stage of the disease when individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases.

Individuals at this stage need help with much of their daily care, including eating or using the toilet. They may also lose their capacity to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing is impaired.

Alzheimer's: Challenges of Communication

Communication between a patient and their family/caregivers is greatly challenged due to affects of the disease.

- Word finding difficulties
- Make up words: "hand clock" instead of watch
- Can't speak in complete sentences
- Forgets English, if it is a second language
- May not understand what you are saying
- Inability to speak (but may understand)
- Problems reading and writing
- May not speak but can sing or recite prayers, poetry

Alzheimer's: Caregiver's Role and Responsibility

Practice **Compassionate Communication**

Be a good listener

- Express interest
- Don't interrupt
- Focus on feelings
    - Do they look excited or happ

      If so, smile with them.
- Be patient, cheerful and reassuring

The patient may ask the same question repeatedly. This may cause you to feel annoyed or frustrated but understand why the question is being asked.

For example, if the Consumer is worried about missing an appointment and repeatedly talks about it:

Instead of saying, "I just told you! Your appointment is at 2 o'clock!"

Try saying, "I can see you're worried about your appointment. Don't worry, I'm going too. I won't leave without you."

Alzheimer's: Caregiver's Role and Responsibility

Practice **Compassionate Communication**

Facilitate a connection

- Establish eye contact
- Use touch and gestures to help convey a message
- Use a calm, gentle, relaxed tone of voice
- Speak simply, slowly and clearly

Although communication may be challenged and there is difficulty in understanding the message, maintaining a connection shows that you care.

Alzheimer’s: Caregiver’s Role and Responsibility

Practice **Compassionate Communication**

It is important to create an environment with little or no distraction to encourage a positive and successful experience.

Check the environment

- Be in plain view
  - Make sure they can see you
- Avoid bright and dark settings
- Identify a quiet place where you can communicate
- Reduce distractions
  - distractions will make it difficult if not impossible to communicate

Alzheimer's: Caregiver's Role and Responsibility

Practice **Compassionate Communication**

Adjust your approach

- Think ahead
  - Think of what you'd like to say in order to simplify the information
- Give simple instructions
  - As few steps as possible
- Ask one question at a time
  - Avoid open-ended questions because it is difficult for them to answer
- Be mindful of facial expressions and body language
  - Use a "positive" physical approach
  - Make eye contact
  - Move slowly
  - Offer your hand (palm up)
  - **Introduce yourself EVERY TIME!**

Use distractions to prevent the patient from doing something that can be unsafe.

For example, if the Consumer is trying to "go to work":

Instead of saying, "Where do you think you're going? You can't leave by yourself!"

Try saying, "Before you go, could you help me with this for a minute or two?"

Alzheimer's: Caregiver's Role and Responsibility

Practice **Compassionate Communication**

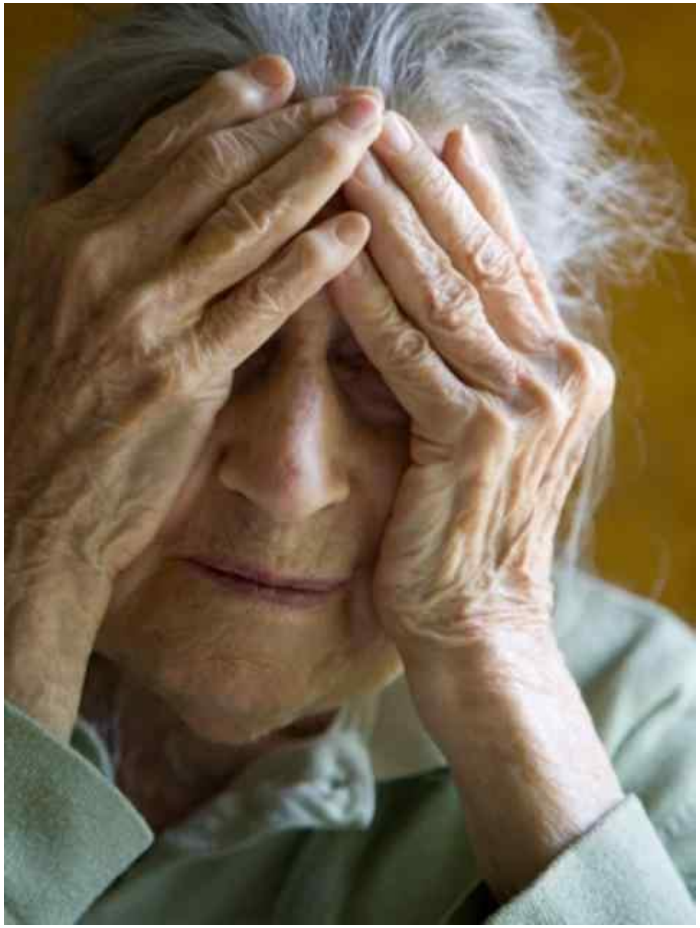
Focus on the skills and abilities of the person

- Encourage activities of independence
- Match the activities to their abilities
- Establish routines
- Give praise and offer compliments
- Respond to their feelings, not words
    - The person may not be able to communicate his/her feelings or needs and may become verbally aggressive out of frustration.
    - Do not take their behavior personally
    - Try to find the reason behind their behavior

Because Alzheimer's disease is progressive and the abilities of the person decline over time, it is important to help him/her remain active and involved in activities/tasks that they are able to accomplish.

Alzheimer’s: Caregiver’s Role and Responsibility

- Avoid exposing the Consumer to:
  - Excess stimulation
  - Loud noise: TV, music, etc.
  - Too much activity
    - Family/friend gatherings
    - Active children
    - Malls
  - Too many visitors in one day
  - Lengthy visits
  - Inconsistent staff
- Help with medication management
- Reduce clutter & remove possible hazards
- Secure stoves and appliances
  - remove/cover knobs
  - unplug and put away electrical equipment where possible
- Prevent driving
- Prevent **wandering**



Alzheimer's: Caregiver's Role and Responsibility

The caregiver's attitude, form of "communication", and response to the Consumer's changes will impact the Consumer's behavior.

It is important to consider that:

- The *disease, not the Consumer,* slowly changes the individual
- Frustration is experienced by EVERYONE; you, the family, and the Consumer
- The individual's behavior is a form of communication NOT a form of rebellion
- Be patient and respond in a calm, supportive, and empathetic manner
    - The Consumer will respond to your non-verbal communication
- Consider the uniqueness of the individual when developing an intervention specific to him/her.
    - What is the individual's condition, his/her perceptions and experience
    - Preferred routines
    - Habits
    - Preferences, likes/dislikes
    - What are their "pet peeves"
    - What effectively distracts the individual
    - What causes calmness or distress

Alzheimer's: Important reminders for caregivers

It is important to understand that their behavior is a form of communication, NOT rebellion.

- It is the *disease* that changes the person; *the person has NO control* over the affects of the disease.
- Look for the reasons behind each behavior
    - Explore pain as a trigger
- Do not argue or try to reason with the Consumer
- **Do not take the behavior personally**
- **Share your experiences with others**
- **"Go with the flow"**
- **TAKE CARE OF YOURSELF**

Resources

alz.org | alzheimer's association®

- Care Consultation
- Caregiver Center
- Family Orientation
- Education and support group programs
  - Families
  - Professionals
  - Social and cultural activities for people with mild memory loss
- www.Trial Match.alz.org
  - Connection to local, clinical trials
- Public Policy and Advocacy
- Medic Alert® + Safe Return®
  - A 24-hour, nationwide emergency response service designed to assist in the return of those who wander and become lost
  - Caregivers can call the 24-hour emergency response line (1-800/625-3780) to report the missing person. Information and a picture of the missing person are faxed to local authorities who conduct the search

24/7 Helpline 1/800-272-3900

alz.org | alzheimer's association

24/7 Helpline
1/800-272-3900

CAREGIVER CENTER

Daily Care

- Daily planning
- Communication
- Incontinence
- Bathing
- Dressing
- Working with doctors

Stages & Behaviors

Education on the different stages of Alzheimer's and tips for caregiving appropriate to the particular stage

Caregiver Support

Information on support groups and caregiver health

Safety Tips

Resources and information to help the patient remain safe: wandering, home safety, driving, medication, etc.

Care Options

- Adult day centers
- In-home care
- Residential care
- Respite
- Hospice

Financial & Legal Planning

- How to plan for care costs
- How to pay/finance costs
- Information about insurance
- Medicare
- Medicaid

alz.org | alzheimer's association

24/7 Helpline
1/800-272-3900

CUTSOM TOOLS

Alzheimer's Navigation

- Guidance to local resources and information
- Help customizing action plans
- support

Caregiver Notebook

- Information on Alzheimer's
- Tips for care giving
- Future planning

Caregiver Stress Check

Self care for caregivers is crucial

- Results from a simple on-line quiz will provide resources for caregiver support

Care Training

- Learn new caregiving and coping skills
- Workshops
- E-learning courses
- DVDs
- Books

Care Team Calendar

- A free, personalized calendar used to organize family and friends who want to help with caregiving

How to show support

WALK TO END ALZHEIMER'S

alzheimer's association®

ALZ OC

November is National Alzheimer's Disease & Awareness Month

Resource

Information for this class was obtained from the Alzheimer's Association.
For additional information and support please contact them at the following:

ALZ
OC

Alzheimer's Association

1/800-272-3900

www.alz.org/oc

Thank you for attending

Any Questions ?