ALZHEIMER'S DISEASE & RELATED DISORDERS
TRAINING FOR PROFESSIONAL CAREGIVERS

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Module 3:
BEHAVIOR PRESENTATIONS
&
ALTERNATIVE CARE TECHNIQUES

Alzheimer's Disease & Related Disorders

TRAINING FOR PROFESSIONAL CAREGIVERS

BEHAVIOR is directly related to ALZHEIMER'S DISEASE---

It is the disease!

It is expected when dementia is present

It is a method of communication

ALZHEIMER'S IS A DISEASE

- ✓ Dementia symptoms are prevalent
- ✓ It is progressive and degenerative
- ✓ No known definitive cause or cure
- ✓ Symptoms can be treated, not reversed Most common of the dementia disorders

Causes of Dementias that may be reversible and/or Treatable

Pseudo dementias include:

Stroke	Alcohol	Stress
Tumors	Thyroid	Depression
Pneumonia	Grief	Dehydration
Infections		UTI
Medication reactions	**Vitamin B12 deficiency**	**Nutritional deficiency**

OTHER DEMENTIA NEURODEGENERATIVE DISEASES

->Multiple Sclerosis ->Cerebellar degeneration

Central Nervous System (CNS) Infections:

->Tertiary Neurosyphilis

->Tuberculous & Fungal Meningitis

->Viral Encephalitis

->Human Immunodeficiency Virus (HIV)

->Acquired Immune Deficiency Syndrome (AIDS)

->Jakob-Creutzeld disease (prion diseases)

Brain trauma (subdural hematoma)

Toxic Metabolic Disturbances:

->Pernicious Anemia ->Folic-Acid Deficiency ->Hypothyroidism
->Bromide Intoxication ->Normal Pressure Hydrocephalus
->Postanoxic or ->Posthypoglycemic states

DIAGNOSTIC TECHNIQUES FOR ALZHEIMER'S DISEASE

The current approach involves ruling out potential causes & finding evidence to confirm presences of others. Autopsy is the only conclusive proof of the presence of AD. Examiner investigates all aspects of the patient's physical, mental, and emotional well-being. As other conditions are ruled out,(example: depression) the examiner is left with a diagnosis of "probable" Alzheimer's disease or related dementia disease.

STAGES OF ALZHEIMER'S DISEASE

Stage 1 EARLY (2-4 years)

- Mild memory impairment begins to affect functional abilities (job, activities of daily living)
- Confusion, mood/personality changes

Stage 2 MIDDLE (2-10 years)

- Diminishing attention span, focus
- Self-care decline
- Delusions & hallucinations are not unusual
- Repetitive statements, loss of language

Stage 3 LATE (1-3 years)

- Can't recognize people, even self in mirror
- Loss of bowel & bladder control
- Bedbound, unable to walk
- Completely dependent on others
- Increased susceptibility to infections/other diseases

KNOWN CAUSES OF ALZHEIMER'S DISEASE & RELATED DISORDERS

- Despite tremendous advances in **Alzheimer's disease research**, many mysteries remain. Research still unable to definitively pinpoint a single or even multiple causes of the disease. The **leading theory** for the past 20 years is the **excess amount of insoluble fragments** of beta-amyloid which leads to loss of brain cell connections. This theory, however, **remains unproven.** Many autopsied brains contain excess amounts of beta-amyloid but no evidence of Alzheimer's disease existed prior to death.
- There are **numerous risk factors** but not necessarily causes for the disease. The distinction between risks and causes is unclear because the biology of the disease is not fully understood. The **most notable risk factors** include: older age, being female, family history, presence of a specific form of the gene apolipoprotein E ($APOE_4$), elevated lipoprotein, cardiovascular disorders (high blood pressure, high cholesterol and heart attack), Diabetes, Down syndrome, head injury and depression.

BEHAVIOR IS:

- ✓ COMMUNICATION
- ✓ ACTION IN RESPONSE TO STIMULATION
- ✓ MANNER OF CONDUCT
- ✓ DEPORTMENT

INTERPRETATION IS:

- ✓ JUDICIOUS USE OF MEANS TO ACCOMPLISH AN END
- ✓ CONDUCT OR SUPERVISE
- ✓ DIRECTING OR HANDLING WITH SKILL
- ✓ MAKE OR KEEP COMPLIANT WHILE TREATING WITH CARE, COMPASSION, PATIENCE
- ✓ GIVE DIRECTION

DO:

BEST TOOLS: distraction - TLC – Music – Touching - Humor

- Make eye contact
- Approach from front, slowly
- Maintain arm's length
- Touch gently
- Give tender loving care
- Reduce environmental noise, activity & distraction
- Address person by name
- Identify self
- Use sense of humor
- Give encouragement & positive reinforcement
- Enhance self-esteem
- Encourage reminiscence
- Observe "feelings"
- Be attentive to facial expression & body language
- Use music to calm
- Pat, squeeze hand
- Simplify environment & tasks
- Stay with early/old memories & songs

DON'T:

- Argue or be defensive
- Rush or hurry or move too quickly
- Do for them what they can do for self
- Raise voice
- Tease
- Be condescending
- Overreact
- Call by endearing or pet names
- Find fault
- Be insensitive
- Leave unattended

COMMUNICATION

- Allow time, patience, slow, be distinct
- One thing at a time, repeat exactly
- Short simple questions & statements
- Never ask "why?"
- Yes & no questions, minimize choices
- Touch (when appropriate) smile, reassure
- One direction at a time

REMEMBER:

STUBBORNNESS EMPOWERS ELDERS & GIVES MORE CONTROL OVER THEIR DEMINISHING LIVES.

WAIT & GO BACK LATER

AGITATION & AGRESSION

- Elevated expectation of person
- Depression, anxiety, fear
- Underlying physical problems, pain
- Environmental factors
- Method of approach

CATASTROPHIC REACTION

Occurs when situation overwhelms the thinking & functioning capacity of person with dementia

Resulting behaviors may include:

- ✓ Rapid mood changes
- ✓ Wandering
- ✓ Anger
- ✓ Blushing
- ✓ Crying
- ✓ Stubbornness
- ✓ Pacing
- ✓ Striking out
- ✓ Paranoia
- ✓ Wringing hands
- ✓ Agitation
- ✓ Yelling
- ✓ Screaming out
- ✓ Spitting

TRIGGERS:

- ✓ Excessive questions
- ✓ Feeling insecure – vulnerable
- ✓ Accidents (spill liquid, soil self)
- ✓ Strange, unfamiliar places, loud noises
- ✓ TV violence, quick scene changes
- ✓ Being asked "Why?"
- ✓ Arguments – scolding, shaming
- ✓ Contradictions
- ✓ Confusing environment
- ✓ Approached from behind
- ✓ Attitudes that project irritation, impatience or frustration

HELPFUL REACTIONS

- ✓Remain calm, patient
- ✓Remove calmly, slowly from stressful situation
- ✓Use distractions
  - new subject or activity, change rooms
- ✓Reduce confusion with memory aids: (examples: Pictures, purse, children)
- ✓ Maintain routine
- ✓ Simplify activities & choices
- ✓ Encourage – give positive feedback often
- ✓ Allow plenty of time for request
- ✓ Take a walk
- ✓ Offer something to eat (ice cream!)

EXPECTED DAILY BEHAVIOR

- ✓ Mood changes, insults
- ✓ Seeing & hearing things
- ✓ Living in the past
- ✓ Talking to self
- ✓ Repetitive actions
- ✓ Losing or hiding things
- ✓ Pacing – Wandering – Fidgeting
- ✓ Clinging – (may speak of mother, spouse, children)
- ✓ Sense emotional climate of their environment
- ✓ Silence – anxious at sundown (activity best in morning)
- ✓ Repetitive statements, stories or questions
- ✓ Clothing irregularities: don't match, underwear over outer clothes

COMBATIVE BEHAVIORS

Potential effective distractions:

- ✓ identify unmet needs
- ✓ Address/prevent by meeting needs
- ✓ Allow private, quiet space while still keeping in view
- ✓ Allow adequate time to complete task/activity
- ✓ Limit interference, step away
- ✓ Avoid negatives (“no”– “you can’t” - “stop”–”don’t ”)
- ✓ Modify body language before calmly re-approaching

The ABC Model of Behavior Management

ANTECEDENT:

Refers to event or activity that results in a behavior. Thought to trigger behavior, whether positive or negative. In determining the trigger, we can encourage good behavior & discourage negative behavior.

BEHAVIOR:

The action that is being observed, analyzed & dissected. Occurs as direct result of antecedent. Is understood in the context of the antecedent activity.

CONSEQUENCE:

The result of the observed behavior. The key component to managing behavior. Depending on the consequence, the behavior itself will either be reinforced or altered.

How to use ABC MODEL

First find the cause of the behavior, then analyze the results of that behavior, then decide a course of action to alter future outcomes. To alter negative behavior, look at the antecedent and the resulting consequence. Alter the contributing antecedent activity in an attempt to alter the resulting behavior. Provide consequences that reinforce positive behavior.

BOREDOM:

"THE GREATEST CONTRIBUTOR TO AGITATION!"

"IF AN ACTIVITY WOULD BORE OR UPSET YOU, THEN IT WILL MOST LIKELY BORE OR UPSET A PERSON WITH DEMENTIA"

NEGATIVE BEHAVIORIAL PRESENTATION

ALWAYS ASK YOURSELF "WHY?"

AND THE ANSWER CANNOT BE BECAUSE THE PERSON HAS DEMENTIA!

ALTERNATIVES TO CHEMICAL & PHYSICAL RESTRAINTS

- ✓ Engagement therapy
  - Encourages purpose & productiveness
  - Adds meaning & fulfillment to live
- ✓ Spaced Retrieval techniques
  - Help person respond to command cues
  - Contribute to higher level of personal success
- ✓ Montessori Method
  - Enables successful engagement in larger community
- ✓ Habilitation
  - Focus on their reality by personal interaction on their terms
  - Allows connecting emotionally

ALTERNATIVES CON'T:

- ✓ Say "NO" to behavior-calming drugs
  - fewer risks, often better outcomes
- ✓ Alter environment (less noise, change lighting)
- ✓ Focus on training staff/family caregivers
- ✓ Create meaningful activities
- ✓ Simplify tasks, establish structured routines
- ✓ Assess for "hidden" medical issues (urinary tract infections, dehydration, physical pain)

BEHAVIOR MODIFICATION

- HOW TO achieve success:

✓ Approach from front & at eye level

✓ Establish eye contact & wear a smile

✓ Speak with pleasant, moderate voice (adjust for hearing and/or sight impairments)

✓ Eliminate exterior noise (television, computer, machinery)

✓ Simplify environment, eliminate clutter

✓ Help them make choices, enable as much independence as possible

✓ Divert/redirect to regain control

✓ Give them something to hold in their hands

✓ Consider cultural differences, language barriers

CONSIDER PERSON'S NEED:

IS IT:

ATTENTION

REASSURANCE

SECURITY

SAFETY

UNDERSTANDING

COMFORT

SUNDOWNING

AGITATION
ANXIETY
PACING
WANDERING
MUTTERING

POSSIBLE EXPECTED BEHAVIORS LATE AFTERNOON OR EARLY EVENING

POSSIBLE REASONS:

- OVERTIRED
- NATURAL LIGHT
- CHANGE IN ENVIRONMENT
- CIRCADIAN CLOCK DAMAGE
- CHEMICAL IMBALANCE
- DISRUPTIONS IN BIOLOGICAL RHYTHMS

POSSIBLE SOLUTIONS:

- CLOSE BLINDS AND DRAPES
- ELIMINATE SHADOWS IN ROOM
- ENGAGE IN FAVORITE ACTIVITY
- ENCOURAGE RESTING IN RECLINER
- PLAY RELAXING, SOFT MUSIC
- MAKE AREA SAFE IF UNABLE TO ALTER BEHAVIOR

(IF ACTING OUT IS EXTREME AND MAY BE HARMFUL, DISCUSS POSSIBLE MEDICATIONS WITH DOCTOR)

MINIMIZE SUNDOWNER'S SYNDROME:

- MAINTAIN DAILY STRUTURE, ROUTINE
- KEEP ACTIVITIES WITHIN ABILITY
- TURN ON INSIDE LIGHTS, CLOSE CURTAINS
- INCREASE DAYTIME ACITIVITY, LIMIT NAPPING
- LIMIT SUGAR, CAFFEINE, "JUNK" FOOD
- KEEP EVENING ACTIVITIES MORE PASSIVE
- LIGHT HALLWAYS & BATHROOMS
- CONSIDER MEDICATIONS CAREFULLY

CONSIDER SENSORY IMPAIRMENTS:

- CAN'T DIFFERENTIATE NIGHT & DAY
- DON'T RECOGNIZE LIGHT & DARK
- SPACE & TIME ARE NOT RELEVANT
- ALL PERCEPTIONS ARE DEFICIENT & IMPAIRED

AS A LAST RESORT:

Discuss medications with doctor
(Be aware that while a medication may solve one problem, it can create another!)

Caregiver's sleep is essential to cope with the daily care demands

Nap when carereceiver naps
ask a friend or relative to spend an occasional night to relieve you
hire professional relief as needed

Research suggests there may be a biological link/explanation regarding damage to the circadian clock that may contribute to Sundowning.

(The normal release of brain chemicals that promote sleep are compromised.)

Bedrosian, Tracy; & Nelson, Randy; Ohio State University published in "Proceedings of the National Academy of Sciences", February 2012

Module 4:
PERSONAL CARE & ACTIVITIES

Alzheimer's Disease & Related Disorders

TRAINING FOR PROFESSIONAL CAREGIVERS

PERSONAL CARE INCLUDES:

- GROOMING
- NUTRITION
- BATHING
- DRESSING/UNDRESSING
- TOILETING/INCONTINENCE
- SEXUAL BEHAVIOR
- SLEEP

GENERAL HELPFUL HINTS:

- ✓ ALLOW THEM TO DO WHAT THEY CAN
- ✓ FOR AS LONG AS THEY CAN
- ✓ ASSIST WHEN THEY CAN'T
- ✓ ADJUST ASSISTANCE AS NEEDED
- ✓ MAINTAIN A CALM PREDICTABLE ROUTINE
- ✓ TREAT WITH DIGNITY AND RESPECT
- ✓ SMILE, HUG, REASSURE, ENCOURAGE

CONTINUED:

- ✓ TALK CALMLY THROUGH EACH STEP OF TASK, ONE DIRECTION AT A TIME
- ✓ RHYTHMIC MUSIC & SONGS IN PLACE OF SPOKEN WORDS CAN BE EASIER TO UNDERSTAND WHEN IN A VULNERABLE SITUATION

GROOMING INCLUDES:

HAIR CARE
SHAVING
MAKE-UP
NAILS
TEETH

GROOMING

- *Hair*
- Use an easy-to-care-for style.
- Washing hair at the kitchen sink may be easier than in tub or shower.
- Get a hose/spray attachment to make rinsing easier.
- Continue to use the same barber/beautician on a regular appointment schedule.

- *Shaving*
- Supervise shaving for as long as possible.
- An electric razor may simplify the job.
- Women may need help shaving legs & underarms.
- They may need help plucking facial hair or shaving chin.

GROOMING CON'T:

- ***Make-up***
- **Women often stop using make-up early in dementia, others feel better if they continue to use it.**
- **Eye make-up may be too difficult to attempt.**

- ***Teeth***
- **Encourage twice-a-day brushing.**
- **If a person has dentures, encourage continued care and regular checkups. Poor-fitting dentures can contribute to poor nutrition and result in mouth sores and constipation.**

- ***Nails***
- **Encourage people with dementia to continue trimming fingernails & toenails. When you take over, do it twice a month.**
- **It may be easier to trim nails while a person is watching TV or engaged in some other way.**
- **Difficulty with toenails, bunions or calluses may cause discomfort or walking problems. A visit to a podiatrist every six months may be helpful.**

NUTRITION

ENVIRONMENT

- ADEQUATE LIGHTING
- CONTRAST COLORS (DISHES, TABLECLOTH, FOOD)
- ELIMINATE DISTRACTIONS (TV, OTHER NOISES, CONVERSATIONS)
- LIMIT CHOICES
- OFFER LESS FOOD MORE OFTEN
- EXCLUDE ALCOHOL, CAFFEINE, CHOCOLATE
- INCREASE FRUITS FOR SWEET TREATS
- Check mouth for sores, denture fit

APPETITE AFFECTED BY:

MEDICATION SIDE EFFECTS
INABILITY TO FEEL HUNGRY
CONSTIPATION
FORGET TO EAT
MAY NOT RECOGNIZE FOOD AS FOOD

BATHING

POSSIBLE PROBLEMS:

- DEPRESSION
- NO LONGER INTERESTED IN PERSONAL CARE
- ROOM, WATER TEMPERATURE
- LACK OF COLOR CONTRAST OF ENVIRONMENT
- LACK OF PRIVACY
- EMBARRASSMENT
- FEAR OF FALLING, WATER, SOAP ETC.
- BELIEVE ALREADY TOOK BATH
- FORGOT HOW TO PRIORITIZE & PERFORM TASK

HELPFUL SUGGESTIONS:

- SAME TIME, SAME DAY, SAME STEPS, SAME ROUTINE
- ONE DIRECTION AT A TIME, BREAK TASK INTO MANY STEPS
- PERSONAL HISTORY SHOULD DETERMINE PREFERENCE FOR SHOWER OR TUB BATH
- GIVE THEM SOMETHING TO HOLD OR EAT TO DISTRACT
- USE "HAND OVER HAND" TECHNIQUE
- CHECK TEMPERATURE & LIGHTING

DRESSING & UNDRESSING

- **POSSIBLE PROBLEMS:**
  - PHYSICAL ILLNESS
  - MOBILITY LIMITATIONS
  - LOSS OF INTEREST IN PERSONAL APPEARANCE
  - MEDICATION SIDE EFFECTS
  - POOR VISION, LIGHTING
  - EXCESSIVE DISTRACTIONS, CLUTTER, NOISE
  - LOSS OF UNDERSTANDING, SHORT ATTENTION SPAN
  - EMBARRASSMENT, FATIGUE, ANXIETY, PRIVACY ISSUES
- **HELPFUL SUGGESTIONS:**
  - SIMPLIFY INSTRUCTIONS
  - ALLOW PLENTY OF TIME
  - DISTRACT BY SINGING, TELL FUNNY STORY
  - USE HUMOR
  - PROMISE A REWARD (ICE CREAM) WHEN TASK COMPLETED
  - REMOVE WORN CLOTHES IMMEDIATELY
  - LIMIT CHOICES
  - STAY SEATED TO PREVENT FALLS
  - LAY OUT IN ORDER TO BE PUT ON

CHOOSING CLOTHES

- SLIP ON SHOES, NON-SKID, CLOSED TOE
- FAVORITE OUTFIT, (HAVE SEVERAL OF SAME ON HAND)
- OFFER CLOTHES IN SHOPPING BAG AS NEW OUTFIT
- EASY TO PUT ON, WEAR, REMOVE
- ELASTIC WAIST, VELCRO, LOOSE FITTING, SOFT FABRICS

TOILETING & INCONTENENCE

- **POSSIBLE PROBLEMS:**
  - EXCESSIVE FLUID INTAKE, DEHYDRATION
  - MEDICINE SIDE EFFECTS, INFECTIONS
  - FAILURE TO RECOGNIZE SENSATION, URGE
  - WOMEN, WEAK MUSCLES, MEN, PROSTRATE
  - CAN'T FIND BATHROOM, CAN'T UNDRESS
  - CAN'T GET OUT OF CHAIR, BED
  - LACK OF PRIVACY, POOR LIGHTING

HELPFUL SUGGESTIONS:

- SCHEDULE REGULAR TRIPS TO BATHROOM
- RECOGNIZE SIGNALS (FIDGETING, PICKING AT CLOTHES, TUGGING AT GROIN AREA)
- PLACE SIGNS OR PICTURES TO IDENTIFY BATHROOM
- PROVIDE PLENTY OF FLUIDS, BUT REGULATE NEAR BEDTIME

BOWEL INCONTENENCE

- Check for fecal impaction or drug side effects
- Learn bowel schedule
- Monitor diet, reduce fruit, add fiber
- Clean carefully to avoid skin breakdown

SEXUALITY

- POSSIBLE (PERCEIVED) CAUSES:
  - FATIGUE, PRIVACY ISSUES, BOREDOM
  - MEDICATION SIDE EFFECTS
  - NEED TO TOILET
  - MISINTERPRETATION OF ENVIRONMENT
  - SLEEP DISRUPTIONS, LOSS OF JUDGMENT
  - ROOM TEMPERATURE, CLOTHING DISCOMFORT
  - DISORIENTATION TO SURROUNDINGS
  - MISINTERPRET TOUCH SENSATIONS DURING BATHING OR OTHER ACTIVITIES
  - NEED FOR TOUCH OR AFFECTION
  - MAY HAVE ALWAYS BEEN A "FLIRT"

SEXUALITY

- HELPFUL SUGGESTIONS:
  - CHECK CLOTHING, ROOM TEMPERATURE
  - KEEP CONSISTANT ROUTINE & ENVIRONMENT
  - IGNOR REMARKS OR BEHAVIOR
  - RESPOND IN MATTER-OF-FACT TONE WHEN NECESSARY TO ESTABLISH BOUNDARY
  - AVOID REPRIMANDING, REASONING, RATIONALIZING
  - ASK FAMILIES TO SHOW MORE AFFECTION
  - DISTRACT WITH FOOD, DRINK, ACTIVITY

SLEEP

- TROUBLE SLEEPING:
  - REMOVE STIMULANTS FROM DIET
  - KEEP BEDROOM QUIET, COMFORTABLE TEMPERATURE, LOWER LIGHTING
  - DISALLOW DAYTIME NAPPING
  - TRY A WALK, CAR RIDE, SNACK BEFORE BEDTIME
  - MEDICATIONS SHOULD BE LAST RESORT
  - CONFORM TO THEIR PREFERRED SLEEP PATTERN
- EXCESSIVE SLEEP:
  - INCREASE EXERCISE, ACTIVITIES, USE UPBEAT MUSIC DURING DAY
  - INCREASE SOCIALIZATION WITH OTHERS

ADULT DAY SERVICES

- HISTORY:
- The Adult Day Health Care (ADHC) innovation:

  >began in Russia in the early 1920's

- The goal:

  >treat patients outside the regular hospital setting whenever possible.

- Great Britain in the 1930's and 1940's:

  >Created geriatric day facilities.

- In the United States:

  >first center opened in 1945, a second in 1959, and 10 more in the 1960's.

DEFINITION

An adult day care center is:

- a non-residential facility
- activities for elderly and/or handicapped individuals
- Meals/snacks
- social interaction
- May include recreational outings
- May include transportation, counseling, personal care, & general supervision

Adult day care centers:

Are either a social and/or a health care model. Provide a range of interdisciplinary professionals meeting the physical, mental, emotional, and social needs of the participants and family caregivers.

Adult day care centers:

are an interactive, safe and secure environment for participants who require supervised daily care.

Participation in adult day care often reduces:

- **Doctor & Emergency room visits**
- **Hospitalizations & re-hospitalizations**
- **May delay admission to residential long term care**

For participants: who would otherwise stay at home alone, the social stimulation and recreational activities may improve or maintain physical and cognitive function.

For caregivers: ADHC provide respite care, enabling caregivers to work or have a break from caregiving responsibilities. ADHC provides support, restore balance in times of crisis, & enhance overall quality of life for both care receivers and caregivers.

ACTIVITIES AND ENGAGEMENT STRATEGIES

- ☺ DAY BRIGHTENERS:
- **Go outside:** nature is restorative
- **Bring nature indoors:** fresh flowers, sit at window
- **Massage to:** sooth and comfort the soul
- **Play favorite music:** can stir the emotions
- **Invite a pet to visit:** petting, watching an animal can be therapeutic
-
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(Paula Spencer, Caring.com Senior Editor)

ACTIVITIES AND ENGAGEMENT STRATEGIES CON'T:

- ENGAGEMENT BENEFITS:
- Increases serotonin level (reducing anxiety)
- Augment muscle mass
- Enhance/maintain general health
- Decrease pacing/restlessness
- Improve night time sleep patterns
- Prevent boredom
- Stimulate sensory systems
- Encourage conversation
- Reduce sundowning

- CARE GOALS:
- Improve overall quality of life
- Validate feelings
- Encourage independence
- Provide safe, supervised environment
- Cultivate confidence, security, self esteem, w☺ell-being
- Enjoy comfortable experience
- Allow sense of control over life
- Minimize stress with positive stimulation
- Provide pleasurable interaction
- Delay and possibly prevent institutional placement

Research documents that SOCIALIZATION, INTERACTION, STIMULATION is the "best medicine" available for a person with dementia disease.

Results of 2 studies conducted at Pennsylvania State University:

- ✓ Caregivers who used Adult Day Services had lower care-related stress & depressive symptoms. (These benefits continued well over a year).
- ✓ Participants benefited from stimulation and social interaction; were more alert & easier to manage after spending the day at day care.
- ✓ Improvements in behavior are related to positive changes in well-being among caregivers.

Caregivers reported 66% less stress on days their loved ones went to day care.

Zarit, S.H., Stephens, M.A.P.,Townsend, A., & Greene, R. (1998). Stress Reduction for Family Caregivers: Effects of day care use. *Journal of Gerontology: Social Sciences*, 53B, S267-S277.

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PARTICIPANT ENVIRONMENT

- **Adult day care (ADC) facilities:**

- **Social model**: recreation, planned activities and hobbies, safety (fall prevention), opportunities for making friends, visiting, meals and snacks, exercise, (no medical assistance).

- **Medical model:** provides professionals including nurses, social workers, certified nursing assistants, physical, occupational, and speech therapists, activity coordinators. Medications can be administered; vital signs including weight are taken regularly and charted. Personal care including toileting, bathing, nails, hair or other services.

- **Physical environment:**

- The setting needs to be spacious enough to accommodate those with wheelchairs, walkers, and canes to maneuver safely.
- Tables should be sturdy enough to steady *"balance- challenged"* participants.
- Chairs with arms and cushioned for "all day" seated comfort. Easy slide-in and away from tables.
- Adequate lighting in all areas.
- Proper wall mounted grab bars in bathrooms
- Secure entry and exit
- Clean surfaces – floors, tables, chairs, bathrooms, etc.
- Frequent use of hand sanitizer, and gloves
- Sound control, never exceed 85 decibels

- **Mental environment:**

- Access to puzzles, magazines, picture books, games
- Avoid clutter, it can be very distracting
- Give clues to encourage self accomplishment
- Engage in trivia and other word games

- **Social environment:**

- Encourage conversation
- Group participants with similar histories and interests together
- Singing together - karaoke

- **Emotional environment:**

- Establish trust
- Help participants feel safe among strangers
- Allow "supervised" independence
- Validate feelings, encourage discussion
- Use" hand under hand" technique
- Participation raises serotonin level bringing participants to a pleasanter, happier level
- Music stirs memories and emotions

- **Spiritual environment:**

- Allow moments for meditative resolve, rest, relaxation, & energy restoration
- Play hymns and gospel music
- Allow for private prayer time if needed
- Be sensitive to cultural differences

Guidance in the Care of Patients with Alzheimer's Disease

- **Take one day at a time**
- **tackling each problem as it arises**
- **Acknowledge your right to feel angry and then do something constructive to control it**
- **Find satisfaction where you can but do not expect much from the patient**
- **Maintain a sense of humor**
- **Try to put yourself in patient's shoes**
- **Do not assume that the patient does irritating things just to be mean**

PATIENT ISN'T GIVING YOU A BAD TIME

PATIENT IS HAVING A BAD TIME

Objectives:

- ADC improves overall quality of life
- Provides a safe, supervised, trusting environment
- Emphasis on health, self esteem, well-being & quality of life.
- Participants are respected for their individuality, wisdom, and breadth of experience.
- Hours of operation are usually designed to accommodate working caregivers.
- Service aides provide direction, supervision, smiles, loving attention, humor, laughter, and personal touch when needed to reassure participants.

ADC maximizes the functioning level of participants for as long as possible including physical, mental, social, emotional, and spiritual well being.

The goal:

- Delay or prevent nursing home placement
- Keep them out of:
  - Emergency rooms
  - Doctors offices
  - Hospitals
  - Re-hospitalizations

The "*best medicine*" available for declining, frail elders is having "*fun*"! There cannot be a healthier environment than to see smiles, hear laughter, and touch hearts everyday.

Types of Groups Activities

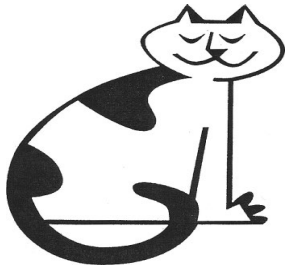
- Dancing
- Walking
- Swimming or water exercise
- Movement to music
- Calisthenics
- Chair or bed exercises
- Simplified "Trivial Pursuit"
- CDs/other music devices
  Audio-visual tapes of dance instructions
  Singing
- Exercising to music
- Working with non-toxic clay
  Making collages
  Painting with water colors
  "Round robin" drawing

Types of Individual Activities

- Sorting and separating different objects
- simplified Alphabet or category games
- Simplified jigsaw puzzles
- version of "Concentration"
- Stringing beads
- Personal playlist, head-phones
- Holding and stroking a dog, cat or rabbit (living or robotic)
- Attending religious services
- Reminiscing about childhood (experiences such as attend-ing church or having Pass-over dinner with family)

Types of Group Activities Con't:

- Watching a hamster or gerbil in its cage Watching birds or squirrels at a feeder placed outside a window
- Listening to a canary or parakeet
- Caring for fish in an aquarium
- Travel films
- Classic television shows
- Wildlife shows
- Documentaries
- Poetry, short stories
- Painting



- Planting small plants, bulbs or seeds in inside containers
- Planting in outside planters, beds or a garden
- Arranging cut flowers in vases or bowls
- Singing hymns or Christmas carols
- Having Bible passages or other religious works read to them

REMINISCING:

- Scrapbooks and photo albums
- Recall historical events using pictures
- Recall past pleasant activities such as travel, food or entertainment
- Develop memory chains (Pick a particular topic, then ask each person in a small group to share a memory about that topic.)
- Recall religious aspects of person's past

Do not use reminiscing therapy unless you know a person's background is comfortable and happy. During reminiscing therapy, unpleasant events and memories from the person's past may resurface and cause emotional and physical distress.

TIPS & TECHNIQUES:

•Provide consistency and structure for people who have dementia. Plan & schedule activities, adjust routine to suit client. Schedule should remain constant, simple and predictable.

•People with dementia will enjoy doing the same activity over and over without getting bored. However, they may enjoy an activity one day, but be disinterested or unable to do it the next day.

More Tips:

- Evaluate the value of activities.
- Activities should suit remaining abilities, knowledge and functional level. Know what the person enjoyed in the past and adapt those activities to present functional level.
- "Busy work" can be appropriate, such as folding the same towels or sorting the same cards.
- Give clear simple, one step, instructions. Point to or talk about an object placed in the person's hands.
- Give positive feedback, encouraging and praising at each step

And a Few More Tips:

- Provide simple, repetitive tasks and avoid overwhelming decisions (ex: offer a choice between two colors, rather than expecting to choose from a whole box of colors).
- Avoid activities that the person with dementia sees as childish, but never deny an activity because you see it as childish. Doing something simple on their own may be one of few remaining pleasures.
- Taking time to prompt the person while dressing may be more therapeutic than dressing them in a hurry so they can go participate in an activity.
- Make the activity fun, use humor, and give positive feedback. Encourage and praise them along each step. Keep the area as free from distractions as possible. People with dementia are very easily distracted.

Module 5:
FAMILY CONCERNS

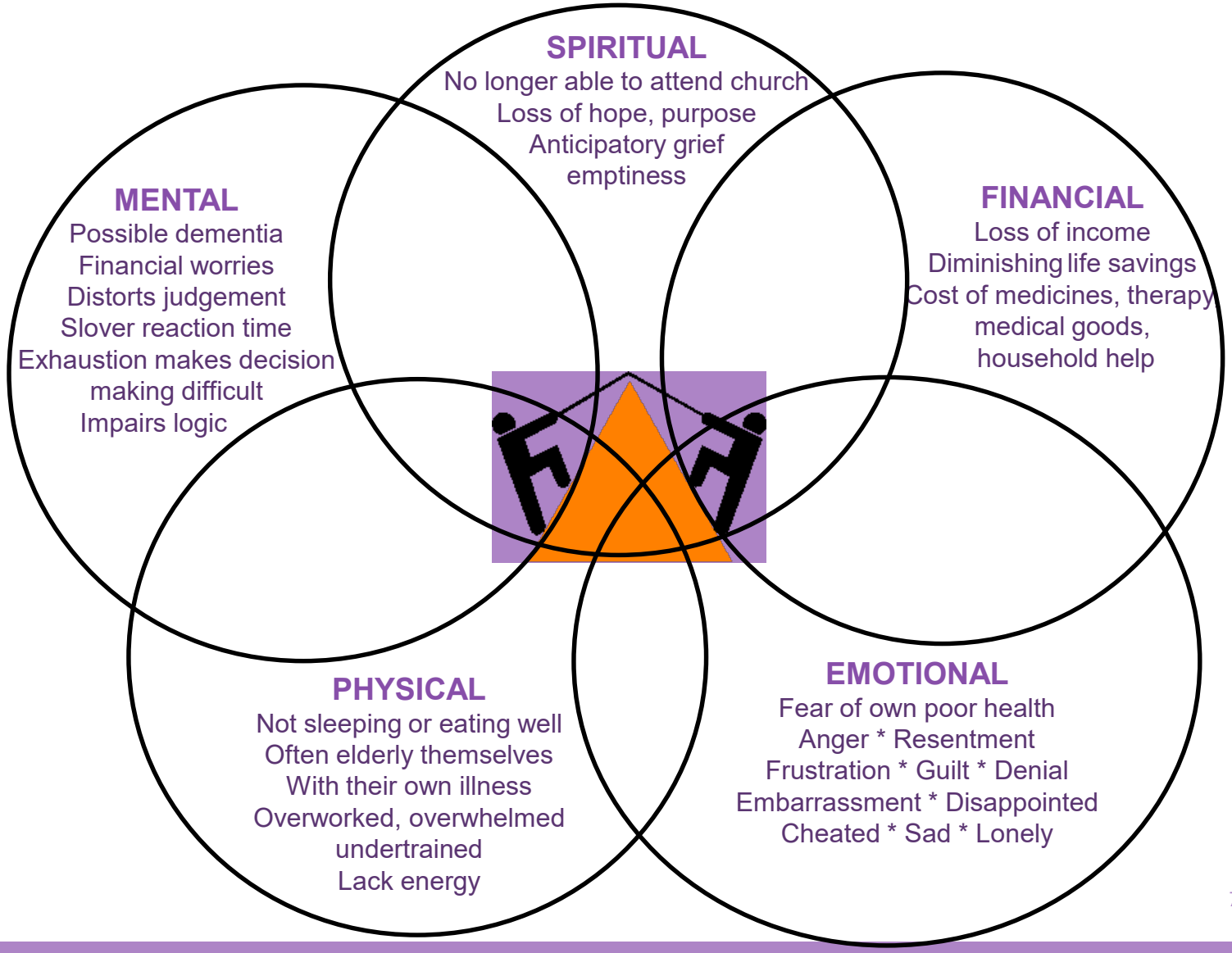
Alzheimer's Disease & Related Disorders

TRAINING FOR PROFESSIONAL CAREGIVERS

Family Issues and Feelings

- ✓ Guilt, Anger, Denial
- ✓ Loneliness, Isolation, depression
- ✓ Collapse of support system. (Family and friends may feel uncomfortable around ill people or around the caregiver and discontinue contact.)
- ✓ Waiting lists for community programs
- ✓ Programs and services refusing to help people needing too much care
- ✓ Role changes and reversals; the parent-caregiver becomes the care receiver
- ✓ Making difficult decisions
- ✓ Conflicting values between family members regarding care
- ✓ Financial burdens
- ✓ Caregiving responsibilities

FIVE WAYS FAMILIES ARE AFFECTED



FAMILY CONCERNS AND ISSUES IN EACH STAGE

EARLY STAGE:

- ✓ Difficulty performing IADLs
  - ✓ Finances, medications, meal preparation, etc
- ✓ PWD lacks self awareness of cognitive changes
- ✓ Need to get financial affairs and other legal documents in order
- ✓ Caregiver Anxiety about the future
- ✓ Families begin to transition into role of caregiver
- ✓ Often forget words, events, appointments, special occasions

MIDDLE STAGE:

- ✓ Caregiver must adapt to decline in PWD language abilities
- ✓ May understand more than can speak
- ✓ Difficulties performing ADLs
- ✓ Increased caregiver involvement in physical care
- ✓ Increased confusion, frustration, difficulty making simple decisions
- ✓ Need for respite and help increases

LATE STAGE:

- ✓ Decisions about need for placement
- ✓ End-of-life care utilization
- ✓ Coping with burnout and pre-death grief

STRESS

CAUSES:

- **MULTIPLE ROLES**

- Responsibilities associated with trying to be all things to all family members, friends, and peers
- Adjusting to changes and losses experienced regarding use of time, lifestyle, well-being, social life, future plans

The Mayo Clinic suggests the following may be signs of caregiver STRESS:

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

EDUCATION AND KNOWLEDGE LEADS TO BETTER COPING SKILLS

Caregivers:

- **have a weaker immune system**
- **see the doctor more**
- **take more medications**
- **have slower wound healing**

(than their peers who are not care giving)

SUPPORT GROUPS:

- **Validate feelings**
- **teach one another**
- **share experiences and ideas for successful coping**
- **encourage expression**
- **promise confidentiality**
- **restore balance in the lives of caregivers**

SYMPTOMS OF CAREGIVER BURNOUT

- Sleep disruptions:
  - insomnia, oversleeping
  - never feeling rested
  - disturbing dreams or nightmares
- Eating disorders:
  - not able to eat or overeating
  - significant weight gain or loss
- Increased use of:
  - alcohol or drug
  - sugar
- Increased smoking or a strong desire to start again after having quit
- Alienation, even from those who offer relief and help
- Frequent headaches, back pain; increased use of over-the-counter pain remedies or prescribed drugs
- Irritability
- High levels of fear or anxiety.
- Impatience
- Inability to handle one or more problems or crisis
- Overreacting to:

>commonplace accidents, (such as dropping a glass or misplacing something)

>to criticism

>with anger toward a spouse, child or older care recipient

MORE SYMPTOMS:

- Feeling emotional withdrawal
- Feeling trapped
- Want to disappear or run away
- No longer laugh or feel joy
- Withdraw from activities and the lives of others around the primary caregiver
- Feeling hopeless most of the time
- Loss of compassion
- Resenting the care recipient and/or the situation.
- Frequently feeling totally alone, even though friends and family are present
- Wishing simply "to have the whole thing over with"
- Playing the "if only" game:
  - "If only this would happen"
  - "If only this hadn't happened"
- Loss of hope, purpose and meaning
- Thinking of suicide as a means of escape
- Neglecting or mistreating the care recipient

Adapted with permission from *Preventing Caregiver Burnout,* James R. Sherman, Ph.D., Pathway Books, 1994, pp. 11-12.

STRESS MANAGEMENT FOR PROFESSIONAL CAREGIVERS

"The care you give is only as good as the care you give yourself!"
P. K. Beville

- **Professional caregivers are not exempt from burnout!**
- **Burnout can affect job performance and personal health.**

SIGNS YOU MAY BE EXPERIENCING STRESS:

- Excessive fatigue or exhaustion
- Waking up feeling tired
- Dread going to work
- Irritable & moody
- Troubled personal relationships
- Physical symptoms:
  - Skin rash, breathing difficulties, high blood pressure, stomach problems, headaches, other unexplained pain
- Difficulty sleeping
- Excessive use of alcohol
- Smoking
- Misusing drugs

CON'T:

- Eating too much or not enough
- Sexual dysfunction
- overreacting to patient's behaviors
- Annoyed by patient's demands and neediness
- loss of interest in job performance

FINAL NOTES:

- Stress & burnout ⇨ inferior job satisfaction & performance
- Safety of patients and caregivers face jeopardy
- Recognize and manage capacity
- Balance personal and professional lives
- Down time is crucial (be it a two week vacation or a 10 minute pastoral break sitting on a park bench)
- Leave job at the office
- Mind your personal time at home
- Address problems, fears, anxieties
- Avoid spiraling into a helpless abyss
- Use relaxation techniques & meditation
- Enjoy a hobby that compliments YOU!

IT'S ALWAYS OK TO ASK FOR HELP!

GRIEF AND LOSS

Source: On Death and Dying: DENIAL, ANGER, BARGAINING, DEPRESSION, ACCEPTANCE written by Elisabeth Kubler-Ross

- **DENIAL** - Reality is painful, Not true, Not happening, A mistake
- **ANGER** - Frustration, Resentment, Rage, Not fair! Why me?
- **BARGAINING** - Rationalization - I can cope if only---
- **DEPRESSION** – Hopeless, helpless feelings – Crying, extreme Sadness
- **ACCEPTANCE** - Makes peace with situation - Makes plans - More objective & realistic - A hoped-for stage; peace and dignity

Grief and loss is not specific to any one stage of the disease. When dementia diseases are present, grief and feelings of loss are ongoing as capacity of person with dementia declines. Caregivers often experience all 5 stages listed as each loss of capacity occurs.

DEFENSE MECHANISMS

Keep:

- **world at arm's length**
- **keep from sharing true feelings**
- **keep from facing facts**

BLAMING (Low self-esteem)

JUDGING (Insecure)

PROJECTING (Stuck up)

PATRONZING (Arrogant)

EXPLAINING (Justifying)

INTELLECTUALIZING (feels inferior/superior, Easily bored, Few friends)

GENERALIZING (Role of victim)

PEOPLE PLEASING (Co-dependent, rescuer)

WITHDRAWING (feels rejected, passive)

DEPRESSED (Poor me! Life is awful!)

JOKING (Shamed of self)

THREE PHASES OF GRIEF

PHASE ONE: SHOCK

- Talk
- Be with people share feelings listen to others feelings
- Counsel with professionals
- Use support group

PHASE TWO: ADJUSTING

- Realize loss
- Be physically active
- Engage in quiet time
- Write down feelings (Keep diary)

PHASE THREE: THE NEW NORMAL

- Seek company when lonely or isolated
- Try something fun
- Be with people
- Renew friendships
- volunteer

As person with dementia passes from one stage to the next, caregivers must proceed through each phase of grief---overcoming the **SHOCK** of another loss; **ADJUSTING** to the changes; accepting a series of **NEW NORMALS** in the disease process.

INSTITUTIONALIZATION
CONNECTING CAREGIVERS WITH PATIENTS

Caregivers role:

- Choose placement that allows frequent visits
- Caregiver's presence reduces fear & disorientation in new environment
- Surround with familiar items or family pictures
- Offer assistance at mealtimes or with other needs as recommended by staff
- Help staff to know the patients history, their likes and dislikes
- Avoid too many family visitors at the same time, it is difficult for the patient to process excessive stimulation
- Be involved in care plan and pharmacological plan
- Speak when the patient cannot
- Know the difference between helping and interfering
- Note cleanliness and safety
- Interact with staff and other patients to learn about their satisfaction, happiness, and comfort
- Be involved in social activities as appropriate and when invited
- Bring family pictures, scrapbooks, greeting cards etc. with you for visits
- Don't be hurt if they don't recognize you, they will remember they enjoyed a visitor
- Above all, don't abandon the patient in skilled care

Module 6:
SAFETY ISSUES

Alzheimer's Disease & Related Disorders

TRAINING FOR PROFESSIONAL CAREGIVERS

SAFE AT HOME AND ELSEWHERE

DRIVING
MEDICATIONS & OTHER SUBSTANCES
FALLS
LIGHTING & REFLECTIONS
WANDERING
IDENTIFICATION
KITCHEN CARE
BATHROOM

A **person with DEMENTIA** can go from:

- ✓ **"NOT THAT BAD"** ➡ **"DISASTER"** in a moment
- ✓ What you see on the **outside** , not what's on the **inside**
- ✓ can't physically **"see"** decline but diagnosis confirms the brain is shrinking

FULL-TIME SUPERVISION IS IMPARITIVE! A PERSON WITH DEMENTIA IS UNPREDICTABLE AND SHOULD NOT BE LEFT ALONE!

GUNS AND OTHER POTENTIAL WEAPONS SHOULD BE LOCKED UP (BETTER YET, REMOVED FROM THE HOME).

POWER TOOLS, OTHER CONSTRUCTION & CARPENTER TOOLS, GARDEN TOOLS, STEP LADDERS, KITCHEN KNIVES ARE ALL POTENTIAL HAZARDS FOR DISASTER.

Driving:

- Loss of driving privileges is difficult and traumatic .
- Driving is associated with independence & freedom.
- Enlist the aid of the doctor, the motor vehicle department, an understanding police officer, a respected family member.
- Remove or disable the vehicle.
- File the key or remove battery from fob so it is inoperable.
- A diagnosis can render insurance null/void. Check the liability.
- As the dementia progresses, may forget they no longer drive.
- Do not leave Car keys where *they* can be seen or found.
- Substituted other keys.
- Simply say, "Your car is being repaired. I'll take you where you want to go."
- Use DMV medical reporting form

Medications & Substances:

- Supervise drug/substance use of persons with dementia
- A missed dose or double dosing can be life threatening
- Deliver prescription, over-the-counter, vitamins, supplements as prescribed or recommended & on schedule
- Install locks on medicine cabinets
- **Alcohol** can cause disorientation and confusion and can interact negatively with medications.
- Substitute with non-alcoholic wines/beers
- Serve **decaffeinated** coffees and teas.
- Smoking presents both a fire and health hazards. (May forget when had last cigarette and become a chain-smoker. Sometimes, a person quit years ago, but forgets he no longer smokes and resumes the habit.)
- **Take *charge* of cigarettes and lighters**

Falls:

- **The most common injury in the home is falling**. (In dementia: perception, balance and dexterity may be affected.)
- **Remove scatter rugs**
- Keep **pathways clear** of furniture, electric cords and clutter
- Stairs/steps should have non-skid tread & sturdy handrails.
- Avoid **smooth-soled shoes, sandals or slippers,** or wearing socks on uncarpeted floors
- **Contrasting colored tape** in **doorways** & on **edges of steps** helps alert the person that they are approaching stairs or entering another room
- **Colored decals** on **glass doors** and large windows helps person recognize that they are closed
- Person with dementia 3 times more likely to fall than others same age due to sight impediments, thinking impairments, balance instability, movement/mobility coordination

Lighting & Reflections:

- Check for **adequate lighting throughout home.**
- Keep lighting soft and/or indirect to **avoid glare**
- **Night lights** in hallways, bedrooms and bathrooms can avoid nighttime mishaps.
- **Illuminated light switches and timers** for night lights are helpful.
- Blinds, shades or sheer draperies block bright sunlight.
- **Avoid reflections** which can confuse and agitate *a* person who has dementia. (Sometimes, reflections are perceived as people looking in the windows.)
- It may become necessary to remove or **cover mirrors,** glass-top or highly polished furniture.

WANDERING:

- Place Deadbolts/locks both **high & low** on **exterior doors**
  - Use several **locks** to slow & complicate exit
  - Use different types of locks that require different skills to open
- Disguise door with curtain or mural (Dutch doors or folding doors can be used to hide entrances to kitchen, stairwell, work and storage areas.)
- **Remove bathroom and bedroom door locks**
- **Signs and pictures** can prevent entry into certain areas. (Messages might read: "stop"; "Detour"; "Do Not Open"; "Danger"; "Men or Women Only"; John, Do Not Open this Door"; "Door is Broken, Use Other Door". Pictures of authority figures, such as policeman or soldier or sentry may be effective)
- A large **black mat** placed in front of **exterior doors –** or doors to areas you wish to restrict - can be helpful. (Most with dementia perceive this as a hole and will not step on it.)
- **Door** alarms & beepers alert Caregivers when doors are opened. Baby monitors may be useful.
- **Pressure pads** and **clip-on devices** set off an alarm when a person gets out of bed. (shaker alarms vibrate bed/pillow for the hearing-impaired caregiver)

Identification:

- **Project Lifesaver** is a radio frequency ankle bracelet. The program is administered by the Sherriff's Dept.
- Shoes with built in GPS system enables quick recovery of wandering dementia person
- **National Alzheimer's Association** has an on-line tracking system.
- **Personal information** should not be carried. It may provide devious persons with criminal intent to take advantage of a dementia person.
- New and innovative technology is being invented and being used in creative ways in the home, and elsewhere to protect vulnerable adults.

Kitchen:

- **Child-proof locks** and doorknobs can be used on **kitchen cabinets** where knives, appliances, cleaning fluids and other poisonous substances are stored.
- Remove **the knobs** from **stove** or install a **hidden shut-off mechanism.**
- May need to **disconnect the garbage disposal.**
- **Automatic shut-off devices** should be used on appliances such as **coffee maker, iron and toaster oven.**
- Insert **plastic covers into electrical outlets** when not in use.
- **Check temperature of foods & *beverages*** before serving.
- Set **the hot water-heater at 120 degrees**
- Monitor refrigerator pantry for spoiled/outdated food
- They may try to eat **inappropriate substances** such as **pet food, houseplants, room fresheners** or **candles** which are scented or shaped like edibles.

Microwave:

- **Sealed containers—** or eggs **—can explode** in the microwave.
- Inappropriate items, such as the TV controller, can be cooked and ruined.
- Metallic items can damage the oven, start a fire, or become so hot they cause a serious burn.
- Foods may get so hot a person could be seriously burned trying to remove or eat them.
- (Newspaper ink is flammable. A dementia elder may try to dry rain- drenched paper in oven and cause a fire.)
- **Disconnect, unplug,** install a **remote switch** or **timer** when not in use. (install a **child-proof lock** on the door.)
- **REMEMBER: MICROWAVE OVENS** were not part of their kitchens when they were young.

Bathroom:

- **Remove electrical appliances** (electric razors, hair dryers, radios) from the bathroom.
- **Heat lamps** should be **installed in the** ceiling (less danger of being knocked over, dropped into the tub or touched by wet hands.)
- **A walk-in shower is best; use a shower or bathtub seat**
- Replace towel bars with **grab bars,** properly installed on studs.
- Install Non-slip floor & non-slip shower/tub tape to prevent falls.
- Add a **hand-held shower head** to direct water flow
- **Automatic faucet shut-off devices** can avoid possible water damage from a sink overflowing. (**Electric-eye faucets or the Water Wand** are designed for people who have difficulty turning knobs.)
- A flooding alarm can be used in bath, laundry room and other areas where flooding or leaks are likely.

APPENDIX

Alzheimer's Disease & Related Disorders

TRAINING FOR PROFESSIONAL CAREGIVERS

OBJECTIVES

- **Devices:**
- Personal alarms to alert staff
- Facility alarms to prevent leaving unnoticed
- Use canes, walkers, railings, grab bars
- Respect privacy when using cameras, monitors, etc.
- Use adequate lighting
- Respond to call buttons even when used excessively (think about reasons why it may be used excessively!)

Daily Routine:

- Importance of same daily schedule
- Follow same steps through each activity of daily living
- Promote feelings of safety and security by following same rules of daily engagement
- Maintain orderly, clutter-free environment in all rooms and throughout facility
- Talk patient through each step of activity as you go

Staffing:

- Familiarity is important
- Transfer of trust from staff shift to shift
- Be sympathetic to comfort (temperature, frequent mobility, tasty food)
- Good clinical notes in patients' charts can help prevent catastrophic reactions to change
- Validate patients concerns (For example: if they think they lost something, help them look for it until you can distract them)
- Never forget that you are the patients "Helpline"!

ETHICAL CONCERNS

CONFIDENTIALITY – CONFIDENTIALITY – CONFIDENTIALITY

AUTONOMY:

The right to self-determination and the capacity to determine one's own destiny and as such needs to be respected. Right of an individual to refuse medical treatment and for a doctor to refrain from intervening against a person's choice. An autonomous decision is one made freely, without influence, by a competent, sometimes appointed person. Freedom to move about as long as not a danger to self.

JUSTICE:

Moral obligation to act on the basis of fair adjudication between competing claims. It involves fairness, entitlement and equality. Protection against attitudes, prejudice and discrimination that are often shown toward devalued persons.

BENEFICENCE:

Being kind, loving, charitable toward persons at risk. Involves balancing the benefits of treatment against the risks and costs involved. Sometimes excessive harm/pain may be involved but must be weighed against the long term overall desired outcome in the future.

NEVER FORGET:

This is the patients' home, you may work there but you are also a guest in their home! You work your shift and then go home, they ARE home!

RESPECT IS RECIPROCAL

RESPECT THE PATIENTS RIGHT TO HAVE RIGHTS!

- **Respect their home**
- **Respect their right to privacy**
- **Respect their property**
- **Respect their right to autonomy**
- **Respect their right to make choices**
- **Respect their right to expect your respect**
- **Earn mutual respect through shared trust and honesty.**

When assisting patients with personal/medical care:

- Use the privacy curtain
- Shut the door
- Cover exposed body
- Don't disrobe them in front of others
- Pay attention to task (For example: it is not appropriate to have personal discussions with other employees when feeding, changing diapers or bathing a patient, etc.)
- Don't talk ABOUT them, especially in front of them, talk TO them!
- Interact with patients; give them the undivided attention they deserve and they often crave

Remember:

Patients are human beings with a history and a personal life, they are not just your job! Learn from them, they all have a story to share. BE A PATIENT LISTENER!

Use empathy in making care decisions and choices:

- If you are the patient, how do you want to be treated?
- How do you want others to treat your mother, brother etc.?

Adaptation:

- Listen to the patients even when they are demanding, stubborn, and unpleasant! They are where they are because they are sick, immobile, declining and giving up their independence. Ask yourself how you might react in the same situation?
- They are afraid of the circumstances, they are afraid they will never go home.
- Validate their fears, pains, losses.

THEY ARE NOT GIVING YOU A BAD TIME,
THEY ARE HAVING A BAD TIME!

CASE STUDIES FOR DISCUSSION:

During discussion keep in mind the patients right to self-determination, right to choose and refuse even when their own well being may be compromised or jeopardized. Consider the rights of all persons involved.

CASE #1:

- The patient is Jewish while his roommates/tablemates are Christians. He is offended at the sight of Christian symbols used in decorations, songs etc. used at holiday time. (Or the patient may not have expressed concern but the family members are disturbed by these symbols being displayed when they visit.)

How can this situation be resolved so the cultural beliefs of all parties are respected?

- **Ethical considerations:** Invite offended parties into a dialogue to promote better understanding of their religious diversity. Reassure all parties that their autonomy is respected and their rights are protected.
- **Consider:** inclusion of both cultures, separate religious services, and……

CASE #2:

The patient refuses to take her medications. She accuses the nurse of trying to poison her and further, wants to know why she is being held prisoner in this place. How can the nurse distract and redirect the patient and in the process convince the patient that she can trust the nurse and that the nurse is her friend and would not intentionally hurt her?

Ethical considerations: Remind and respect patient's right to self-determination. Weigh competence against capacity to make own choices and decisions and use professional resources in the process.

Consider: changing environment, change meds schedule, change how present meds, reassure, reassure, reassure, and…. TRY AGAIN LATER!

CASE #3:

Late in the afternoon, the patient regularly becomes excessively agitated and aggressive. The patient is Sundowning. He lashes out both verbally and physically at those trying to restrain and comfort him. He will throw anything he can get his hands on. He often hallucinates. Clearly his anxiety level is "over the top!" How can this behavior be quelled, the patient subdued, and everyone's safety restored?

Ethical Considerations: Maintain moral respect for the situation realizing that the patient may not be able to sense any responsibility for his/her actions. As care providers our obligation is to maintain the patients' safety and wellbeing. We may not inflict our own judgment regarding the appropriateness of the behavior.

Consider: change tone of voice, body language, facial expression, offer favorite drink or snack, back off but remain close by to insure safety and…..

EARLY STAGE CONCERNS & ISSUES:

- Get legal documents and financial affairs in order while patient can participate in decisions
- Develop coping skills to deal with reality of, sadness & fear associated with diagnosis
- Educate on disease symptoms & progression
- Expect some denial, avoidance, regret
- Often overwhelmed, worried and anxious

MIDDLE STAGE CONCERNS & ISSUES:

- Develop care plan that includes family & friends
- Accept help; use respite; no longer able to stay alone
- Resentment toward loved one
- Bitter/frustrated/guilty about ability to care for loved one
- Depression
- Grief over successive loses

LATE STAGE CONCERNS & ISSUES:

- Burnout, exhaustion, loneliness, despair, depression
- Prepare for end-of-life care
- Acceptance of loss, deterioration