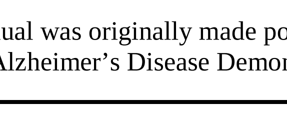
Participant Workbook

The Person Comes First:
A Practical Approach to Alzheimer's Care

Required training for the

Family Alzheimer's In-Home Respite (FAIR) Program
West Virginia Bureau of Senior Services



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The Person Comes First:
A Practical Approach to Alzheimer's Care

Course Objectives

At the conclusion of this training, participants should

- Have a better understanding of Alzheimer's disease and related dementias, including early signs, diagnosis, and stages of the illness.

- Know general principles of communicating with an individual who has Alzheimer's disease or a related dementia and understand both verbal and non-verbal techniques that may be used to overcome communication challenges.

- Have a better understanding of behaviors that may occur as a result of Alzheimer's disease or a related dementia, understand reasons those behaviors may occur and know some appropriate ways to respond to those behaviors

- Be able to define what an activity is, and understand the purpose and importance of activities to enhance an individual's quality of life.

- Have a better understanding of how this disease affects families and the adjustments family members go through as the disease progresses.

- Most of all, understand the importance of knowing the person for whom they are providing care and treating each person as a unique individual, worthy of dignity and respect.

Session I

Defining Dementia and Alzheimer's Disease

Defining Dementia and Alzheimer's Disease

Beginning Exercise: Getting to Know You

Definitions *(included in Participant's Workbook)***:** We'll be using the following two terms throughout the day, and we want to be certain that everyone is clear on the definitions:

- **Dementia** describes a set of symptoms – memory loss, confusion, behavior changes, personality changes – that are severe enough to interfere with normal daily activities. This is the generic term, and many conditions can cause dementia.
- **Alzheimer's disease** is a physical disease of the brain that results in impaired memory, thinking, and behavior. It generally has a gradual onset. It is progressive, degenerative, and irreversible, eventually leaving individuals totally unable to care for themselves. Alzheimer's disease is the most common form of dementia.

Two other related terms that you should know:

- **Reversible dementia**, a condition which is treatable, with the person potentially returning to his or her normal state. It may have a physical or mental cause, including dehydration, infection, thyroid imbalance, diabetes, reaction to medication, and psychiatric problems. When the underlying medical or psychiatric problem is successfully treated, the symptoms of dementia disappear.
- **Non-reversible dementia**, which is progressive, degenerative, and irreversible. The most common non-reversible dementia is Alzheimer's disease. Other forms include vascular dementia, diffused Lewy Body disease, Pick's disease, Huntington's disease, and Parkinson's disease.

Today we'll be talking about non-reversible dementias, especially Alzheimer's disease. We'll use both terms – dementia and Alzheimer's disease – to refer to individuals for whom you will provide care.

Background Facts on Alzheimer's Disease *(Included in Participant's Workbook)***:**

- Alzheimer's disease was first diagnosed in 1906 by Dr. Alois Alzheimer.
- It is <u>not</u> a normal part of aging.
- There are more than 5,000,000 Americans with Alzheimer's disease (5.4 million in 2011), approximately 44,000 of them West Virginians over the age of 65.
- Two-thirds of those with the disease, 3.4 million, are women.
- Keeping heart disease risk factors under control (blood pressure, cholesterol, blood sugar, weight, etc.), eating fish rich in Omega-3 fatty acids, exercise, interacting with others, and lifelong learning may help prevent or at least delay onset of Alzheimer's.
- At the present time, Alzheimer's disease is fatal. There is no cure.
- There are four medications on the market – Aricept, Exelon, Razadyne, and Namenda – that may delay symptoms for some individuals. Aricept, Exelon and Razadyne are prescribed for mild to moderate Alzheimer's disease. Namenda works on a different receptor in the brain and was designed to treat moderate to severe Alzheimer's. It is frequently given in conjunction with one of the other three. Dozens of other drugs are currently being studied to determine if they are safe and effective medications for the treatment of Alzheimer's disease.
- There is a big scientific push to determine who is most at risk for Alzheimer's disease, thus to be able to predict who is likely to get the disease before symptoms ever appear. The best chance for stopping it is to be able to treat it before it really takes hold. That would be possible if we had the right treatment, because **the disease process for Alzheimer's starts twenty years or more before you ever see the first symptom.**
- Several potential vaccines are currently being tested on humans.
- There is a genetic component to Alzheimer's disease, with <u>early onset</u> Alzheimer's being more directly hereditary. **Early onset Alzheimer's disease occurs in individuals in their 40's, 50's, and possibly early 60's.**
- **The number one risk factor associated with <u>later onset</u> Alzheimer's is age**. One in ten persons over age 65 and nearly half of those over 85 have Alzheimer's disease.
- Most people survive an average of four to eight years after a diagnosis of Alzheimer's disease, but some live as long as twenty years with the disease.
- On average, 40% of a person's years with Alzheimer's are spent in the most severe stage of the disease – longer than any other stage.

- It is the third most expensive disease in the United States, after heart disease and cancer. The average lifetime cost per patient is close to $200,000.
- More than seven out of ten people with Alzheimer's disease live at home. Almost 75% of the home care is provided by family and friends.
- Neither Medicare nor private health insurance covers the long-term type of care most people with Alzheimer's disease need.

(Compiled from the *Alzheimer's Association's Alzheimer's Disease Facts and Figures, Generation Alzheimer's and WV DHHR's An Overview of Dementia: The Growing Crisis in West Virginia*)

Ten Warning Signs of Alzheimer's

1. Memory changes that disrupt daily life. One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events, asking for the same information over and over, and relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. **What's typical?** Sometimes forgetting names or appointments, but remembering them later.

2. Challenges in planning or solving problems. Some people may experience changes in their ability to develop and follow a plan or work with numbers, for instance, putting together a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. **What's typical?** Making occasional errors when balancing a checkbook.

3. Difficulty completing familiar tasks at home, at work or at leisure. People with Alzheimer's often find it hard to complete daily tasks and may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. **What's typical?** Occasionally needing help to use the settings on a microwave or to record a television show.

4. Confusion with time or place. People with Alzheimer's can lose track of dates, seasons and passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. **What's typical?** Getting confused about the day of the week but figuring it out later.

5. Trouble understanding visual images and spatial relationships. Some vision problems may be a sign of Alzheimer's. Individuals may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and not recognize their own reflection. **What's typical?** Vision changes related to cataracts.

6. New problems with words in speaking or writing. People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock"). **What's typical?** Sometimes having trouble finding the right word.

7. Misplacing things and losing the ability to retrace steps. People with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. **What's typical?** Misplacing things occasionally, such as a pair of glasses or the remote control.

8. Decreased or poor judgment. People with Alzheimer's may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. **What's typical?** Making a bad decision once in a while.

9. Withdrawal from work or social activities. Individuals with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. **What's typical?** Sometimes feeling weary of work, family and social obligations.

10. Changes in mood and personality. People with Alzheimer's can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. **What's typical?** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

Getting a Diagnosis:

The diagnostic process will involve a primary care physician and possibly other specialists. Evaluations may include the following steps:

- **Medical history**
- **Mental status**
- **A series of evaluations that test memory, reasoning, vision-motor coordination, and language skills**
- **Physical examination**
- **Examination that tests sensation, balance, and other functions of the nervous system**
- **Brain scan**
- **Laboratory tests**
- **Psychiatric evaluation**

The results of all of these tests should be evaluated together to determine a diagnosis.

Impact of the Diagnosis:

How do you think you would feel if you or someone in your family got that diagnosis?

Effect of Alzheimer’s Disease on Cognition, Behavior and Emotions

Changes in cognition

- Memory loss
- Learning difficulties
- Language problems
- Decreased ability to reason things through

Changes in behavior

- Communication skills deteriorate
- Safety increasingly becomes an issue
- Activity of daily living skills deteriorate
- Behaviors challenges may develop due to increasing confusion, frustration, and lapses in clarity and comfort

Changes in emotion

- Emotional responses become disorganized and confused
- Apathy, a general flattening of moods, increases (Charlton Heston example)
- Moods may become very changeable, usually in reaction to changes in the immediate situation
- There is more of a possibility of volatile, explosive, or catastrophic reactions, usually provoked by surroundings.

Closing Exercise

Ten Minute Break

Session II

Effectively Communicating with the Person Who Has Dementia

Effectively Communicating with a Person Who Has Dementia

Beginning exercise: How to get to Neptune

What if you were the person who needed care?

If someone were coming into your home to care for you, or if you were being admitted to a long-term care facility today, what would you want people providing your care to know about you? Please indicate below what you would **most** want the person providing care to know about you :

____

____

____

Then complete the following statements:

When I was a teenager, the music I liked best was __________________________.

The name by which I most like to be addressed is __________________________.

At night, before bedtime, my favorite snack is _____________________________.

When I was young, my favorite activities were ____________________________.

My favorite food has always been ______________________________________.

One food that makes me gag is ____.

My greatest fear is ____.

My favorite movie of all time is _______________________________________.

The sport I liked best growing up was __________________________________.

The thing I like most about a bath is ____________________________________.

The thing I dislike most about a bath is _________________________________.

Why challenges with communication occur:

- Short-term memory loss
- Decreased ability to concentrate
- Slowed response to stimuli (takes longer to process what she sees or hears)
- Hearing difficulties
- Vision difficulties
- Inability to read, write or understand what someone says

How challenges with communication are expressed:

- Defensiveness – possibly suggesting that you are the one with the problem
- Word finding difficulties or word substitutions
- Difficulty organizing words/thoughts logically
- Using familiar words repeatedly
- Inventing new words to describe familiar objects
- Reverting to speaking in a native language
- Cursing
- Speaking less often
- Reliance on nonverbal gestures more often – which makes it important for us to learn to interpret non-verbal forms of communication
- Showing frustration through anger, agitation, crying, and/or withdrawal
- Depression

Whatever the challenges and however they are expressed, communicating with individuals with Alzheimer's disease and related dementias involves general principles that apply to most situations.

General Principles of Communicating:

- **Everyone is different.**

- **The individual isn't trying to be difficult – even though it may seem so.**

- **The "reality" of the person with dementia is different from your reality.**

- **Show that you are listening and trying to understand what is being said.**

- **Focus on feelings, not facts.**

- **Put the emphasis on what the person <u>can</u> do.**

- **Prepare the person for what's about to happen**.

- **Assume the person understands everything you say.**

- **Be realistic; be patient.**

- **Do use distraction, or walk away and try again later.**

- **Hang on to your sense of humor, and remember that the person with dementia has one, too.**

- **If a behavior doesn't hurt anyone, either the person with the disease or**
- **anyone else, and <u>if</u> you can put up with it, let it go, especially if you don't**
- **have a good strategy for dealing with it.**

- **What you say and what she hears may be two different things.**

An Exercise in Understanding

Effective Verbal Communication Techniques

Verbal communication is effective with individuals in the early and middle stages of Alzheimer's disease to calm, reassure, and help to complete activities or tasks.

Address the person by name and identify yourself.

Speak slowly and clearly, communicating one message at a time.

- Break all tasks down into simple steps, using short, easy to understand sentences
- Give the individual adequate time to respond.
- If you have to repeat something, use the same words.
- Be prepared to give the information more than once

Keep it simple.

- Emphasize key words; listen for key words.

- Ask family members about possible meanings for words, names, or phrases that you do not understand.
- Avoid open-ended questions.
- Avoid pronouns as much as possible. .

Put the emphasis on the person.
- Use the person's name frequently to keep her focused.
- Validate responses and feelings.
- Show respect.

Non-Verbal Communication

Non-verbal techniques can be used alone or in conjunction with words to reinforce messages or convey safety, comfort, and security. Positive, non-verbal techniques are helpful at all stages of the disease.

Effective Non-Verbal Techniques:

Your tone of voice!
- It's not what you say; it's how you say it.
- She may not understand the words, but the feelings behind them will be communicated loud and clear.
- Your attitude is reflected in your tone of voice.

Your approach
- Approach the person slowly and from the front.
- Make eye contact, and maintain it as much as possible.
- Use physical touch to calm the individual and to keep her attention – hugging, patting, stroking, holding hands, etc.
- Eliminate background noise as much as possible.

Take advantage of the power of body language, expressions and gestures!
- Be calm and supportive.
- Maintain a relaxed posture.
- Be aware of facial expressions. .
- Use gestures to help convey your message.
- Get low, and go slow.

- **Just as with tone of voice, body language, expressions and gestures may convey much more to the person with Alzheimer's than the words you use. Make sure to keep it positive.**

Other Forms of Non-Verbal Communication:

How you dress

- We form opinions about people before we get to know them, and sometimes that opinion is based, in part, on how they dress.
- What you wear sends a message, whether you intend it to or not.

Colors

- Think contrast

Communicating Activity

Skills Building Exercise: Using Verbal and Non-Verbal Communication Techniques

Exercise 1: Lucille gets dressed – or not

Becky, the respite worker, arrives at Lucille's house at 11:00am. Becky finds that Lucille's daughter, Emma, is running late for an appointment, and Emma hasn't been able to convince Lucille, who has moderate Alzheimer's disease, to change from her pajamas and robe to the clothes her daughter has laid out for her. Emma has explained to Lucille several times that breakfast is over and it's time to get dressed. Lucille, who is pleasant to everyone, politely refuses. Emma asks Becky to make sure that her mother gets dressed soon. She tells Becky that if Lucille wears her pajamas and robe into the afternoon, she sometimes gets confused, thinks it's time for bed, and wants to sleep. Then she's awake during the night. When Lucille gets dressed, she's more alert and enjoys watching her Lawrence Welk video after lunch. Sometimes, she even claps and moves with the music. *What can Becky do to encourage Lucille to get dressed? What are things she definitely shouldn't do or say? What could Emma do differently that might make a difference? What's likely to happen if Emma returns and Lucille is still in her pajamas and robe?*

Exercise 2: Tom has somewhere to go

Tom, 77, has been retired for fifteen years and has moderately severe Alzheimer's disease. Some days, he insists that he's late for work and heads out the door for an "appointment." Tom used to like Kathy, the respite worker, even though he can't remember her name from visit to visit. Lately, however, he gets very annoyed with her when she tries to convince him to go back to the house. He doesn't like it when she tries to tell him what to do. Kathy is concerned, though, because she knows that Tom has wandered repeatedly and twice was lost for several hours. She isn't sure what to do when Tom takes off and won't listen to her. She wishes the family had taken some steps to keep him safe.

What is Kathy's first responsibility? What are some of the things she can do or say to convince Tom to go back to his house? What might Kathy say that would ***not*** *help the situation? What are some things Tom's family could do to reduce his wandering and keep him safer, and how should Kathy communicate those ideas to the family?*

Exercise 3: Not politics as usual

Carol is 60, and two years ago, she was diagnosed with early onset Alzheimer's disease. Carol has always been outgoing and energetic and, since she was young, has taken an active part in local political campaigns.   In the time since her diagnosis, she has withdrawn from most activities. Her friends rarely call her anymore; and she doesn't pay as much attention to the political scene. That concerns her husband, Mark, who feels she still has a lot to offer. He has hired Jenny as a companion for Carol, to go with her to events and take some of the stress out of social situations. Jenny is very impressed with Carol's knowledge of local politics when they talk one-on-one, and Carol has expressed frustration at some of the tactics and marketing strategies used by candidates. She even admits that she would like to help certain candidates.

What can Jenny do to make Carol feel more comfortable in public? Do you think Carol could get involved in a political campaign again? What are some things Jenny should ***not*** *try to do for Carol? What decisions can Jenny make on her own, and when should she consult with Mark?*

Session III

Understanding and Responding to Behaviors Associated with Alzheimer's Disease and Related Dementias

Understanding and Responding to Behaviors Associated with Alzheimer's Disease and Related Dementias

Beginning Exercise: Lining Up

Responding to challenging or unpredictable behaviors sometimes becomes the most important part of providing care for a person with Alzheimer's disease or a related dementia. We should make three points right now about behaviors:

1. **The person is not acting this way on purpose.**
2. **It's not personal.**
3. ***You* can adjust your approach to the person and your reaction. The person with dementia cannot.**

Examples of challenging behaviors:

- **Anxiety or agitation**
- **Aggression**
- **Wandering**
- **Suspicion/paranoia**
- **Delusions/hallucinations**
- **Sleep disturbances**
- **Inappropriate sexual behaviors**

Why behavior challenges occur:

- **Other health conditions that affect behavior**

- **Pain/discomfort: As a first step in reducing challenging behaviors, assess for pain and discomfort.**

- **Effects of medication**

- **Depression**

- **The environment –**Confusing, overwhelming, unfamiliar

- **Excessive stimulation**

- **Unstructured environment**

- **Poor sensory environment**

- **Visual/spatial skills**

- **Communication may be difficult**

- **The task itself (what you're asking the person to do)** – May be too complicated or too many steps combined.

Task Exercise

Assessing Behaviors: Through training and experience, those who provide care for individuals with dementia learn that

- It is **your** responsibility to **anticipate** problems or events.
- If you properly anticipate, you may successfully **prevent** problems or events
- If you cannot anticipate problems, you should have an **established method for correcting problems** or events as they occur.

Ways to assess behaviors

There are several ways to assess behavior challenges that may occur. We will briefly present two ways. Ideally, you would be able to use one of these methods to assess a behavior and find ways to prevent it from ever happening again. Realistically, assessing a behavior may help you identify the cause of the behavior and make changes that will decrease the frequency and/or severity of the behavior.

1. ABC Method

B
The Behavior

A
The Antecedent (Trigger)

C
The Consequences

B – The Behavior: Identify the behavior, and look at just one behavior at a time. Observe objectively, and record only what you see.

A – The Antecedent: What happened right *before* the behavior occurred? What triggered it?

C – The Consequences: What happened immediately *after* the behavior occurred? Who responded and how?

Usually, your energy is directed at C, trying to handle the behavior. If you shift your energy to A and find the trigger for the behavior, you may be more effective in managing or even eliminating the behavior.

2. The Eleven "W's" of Challenging Behaviors

There are specific questions you can ask when trying to eliminate or manage a challenging behavior:

1. **Who actually has the challenging behavior, the person with dementia or the caregiver?** (If your answer is anyone *other than* the person with dementia, you do not need to ask yourself the rest of the questions. That person is the one whose behavior needs to change.)
2. What is the specific behavior?

3. Why does it need to be addressed (who is it hurting or bothering)?
4. What happens just before the behavior (trigger)?
5. Where does the behavior usually occur?
6. What does the behavior mean?
7. When does the behavior occur (morning, evening, bath time, etc.)?
8. How often does the behavior occur, and how long does it last? Is there a pattern?
9. Who is there when the behavior occurs?
10. What is the usual outcome of the behavior?
11. What is the **desired** change or outcome you would like to see?

Note that questions 2, 4, and 10 are similar to the ABC method for assessing behaviors. The rest of the questions help you get a complete picture of what's going on before, during and after the behavior.

Use one or both of the following scenarios to illustrate how to assess a behavior:

Scenarios:

A. A female nursing home resident, at the end of every month, wanted her check, thinking that she was still employed. She would become very upset and refused to eat when she didn't get it. One of the staff found an old check, whited out much of the information and made the check out to her. They then cashed it for her with fake money, and she was happy – until the end of the month – at which time they repeated the process.

   What is the actual behavior?
   What happened before the behavior?
   What were the consequences of her behavior?

B. A person with Alzheimer's disease walks out of his bedroom and sees the direct care worker talking with his wife down the hall. He can't hear what they are saying, but he's pretty sure they're talking about him. He starts yelling. The worker and his wife both hurry to him and comfort him.

   What is the actual behavior?
   What happened right before the behavior?
   What were the consequences of his behavior

Above all, you must remain calm at all times, no matter what he says or does. If he is agitated, angry and yelling, you will most likely make the situation worse if you react angrily.

It is worth repeating: Usually, when there is a behavior that seems problematic or erratic to us, our energy is directed at C (the consequences), trying to manage the person after the behavior has occurred. If we shift our energy to A and find the trigger for the behavior, we may be more effective in managing or even eliminating the behavior. In summary

- Determine if this is a behavior that requires attention. If so, pay attention to what happens prior to the actual behavior.
- Consider whether the person is in pain.
- Respond calmly.
- Have a consistent reaction every time you see or hear the trigger, and give it some time to work.
- Know that failure is a possibility. Despite your best efforts, your plan may not work.
- Try again with a new plan until you find one that is successful.

Effective Techniques for Understanding and Responding to Behaviors

- **Get to know the person before trying to assist with ADLs or other tasks**.

- **Have a diversion or way to redirect the person's attention in mind before there's a problem with a behavior.**

- **Remove the person from a situation that is upsetting him, or remove the situation from the person, whichever is more feasible.**

- **Break all tasks down into smaller and simpler steps**

- **Don't rush the person or act like you're in a hurry.**

- **Provide limited choices for the person.**

- **To the extent possible, control noise levels, lighting and temperature**.

- **Give her reassurance, and provide a sense of safety and security**.

- **When necessary, set limits**. **When absolutely necessary, take control of the situation**, **so that certain behaviors do not happen.**

- **Respect the person's privacy and level of modesty.**

- **Do not keep the individual waiting**

- **Establish a plan and a routine based on preferences of the individual.**

Skills Building Exercise: You Are Unique

Session IV

Working with Families

Working with Families

Beginning Exercise

Alzheimer's is a chronic, progressive disease, and people with the disease experience a series of changes or losses. Each change has an effect on the person with Alzheimer's. It also affects family members and requires them to make adjustments. Those changes and losses include

- Getting the diagnosis
- Giving up the car keys
- Incontinence
- Needs 24-hour care
- No longer recognizes most family members
- Seems near death but lives on indefinitely

The process of adjustment involves grief and loss each time there is a change. Grieving before a person actually dies is known as **anticipatory grief.**

There are five stages of grief, as defined by Howard Gruetzner in Alzheimer's: The Complete Guide for Families and Loved Ones:

1. **Denial** – The initial response that nothing is wrong and no assistance is needed.

2. **Over-Involvement** – Trying to meet all the needs of the person with dementia and refusing help from anyone.

3. **Anger** – One result of the physical, emotional, financial and social burden of providing care.

4. **Guilt** – The feeling that you have said something wrong, done something wrong, or had thoughts that were inappropriate

5. **Acceptance** – Having a full understanding of the process of Alzheimer's disease and its effect on the individual, the primary caregiver and other members of the family.

Caregiver Stress: At every stage of the disease and throughout the stages of grief discussed above, caregivers experience stress.

Major causes of caregiver stress:

- **Being overwhelmed**
- **When the spouse is the caregiver and the person with Alzheimer's is younger**
- **When the spouse is the caregiver and the person with Alzheimer's is older**
- **When the caregiver is an adult child or other younger relative**
- **Caregiver fatigue**
- **Other family members**
- **The uncertainty of the future**

Ten Signs of Caregiver Stress: Caregiver stress may be expressed in any of the following ways:

1. **Denial**
2. **Anger**
3. **Social withdrawal**
4. **Anxiety**
5. **Depression**
6. **Exhaustion**
7. **Sleeplessness**
8. **Irritability**
9. **Lack of**
10. **Health problems**

There's a book by Sue Salach, titled Just When U Think U Know What You're Talking About – Along Comes Grandpa! Some of the following lessons she learned through her successes; others through her mistakes and failures. It's good advice that we can pass on to caregivers:

- **Don't try to be everything to everyone**
- **Learn as much as you**
- **Prepare for appointments and take notes**
- **Learn how to say no**

- **Get over being embarrassed by your loved one**

- **Have a schedule/be flexible**

- **Schedule some "me" time**

- **Don't be afraid to get silly**

- **Ask for help; assign responsibilities**
- **Get a regular break**

- **Deal with stress**

Skills Building Exercise:

Scenario 1: The Long-Distance Daughter

The 48-year-old daughter, Jenna, travels from California to visit her mother, Margaret, twice each year. While visiting, Jenna is full of criticism about the care her mother is receiving. She spends hours crying and fretting over her mom, who is in the late-middle stage of Alzheimer's disease and doesn't recognize her daughter most of the time. Frequently, Jenna screams at the worker, asking why she doesn't do this or that differently, and, occasionally, even calls the senior center to talk to the worker's supervisor. She wants to know what you are doing that is upsetting her mother. All of this is disturbing to Margaret, who becomes more agitated during her daughter's visits.

How would you, as the worker, deal with Jenna? As a staff person at the senior center, what would you do or say if she called you? How could you help Jenna understand the situation better, and what could you do to avoid future confrontations?

Scenario 2: The Large Protective Family

Harry's children and grandchildren stop by frequently to check on their dad/granddad. Harry enjoys their visits but sometimes can't remember who they are, especially the grandchildren. That upsets him and triggers behaviors ranging from verbal combativeness to withdrawal and sadness. Each family member has a suggestion for the worker on how "to bring him out of it," and the worker, not wanting to upset anyone, tries them all, which only upsets Harry more. After they leave, Harry is still upset and doesn't want to talk or take part in any activities.

Who should deal with the family, and how? What can you do to keep Harry from getting so upset? How can you turn their concern for their dad/granddad into a positive for both the family members and for Harry?

Scenario 3: The Worn-Out Husband

As a respite worker, you know you're in the Nelsons' home to give Mr. Nelson a break from his caregiving responsibilities. He's been caring for his wife, Adele, who has late stage Alzheimer's, for seven years and rarely leaves her for anything. He seems delighted that you're there. He talks about all the things he needs to do and errands he needs to run. He mentions how tired he is from caring for Adele without any help – then feels guilty for saying that. You assure him that you understand and that it's okay for him to get away for a little while, but he won't leave or even go in another room and take a nap. You can see his physical and emotional health declining, and you're concerned about him.

How can you convince Mr. Nelson that caring for his wife is taking a toll on his own health? What can you do to help him deal with the guilt he feels? Should you get anyone else involved? If so, whom?

Remember: You and the family want the same thing – good care for the person with Alzheimer's disease. Build on each other's strengths – you're on the same team.

Session V

Making Activities Meaningful

Making Activities Meaningful

Beginning Exercise

Under normal circumstances, people choose to do things that

- **They feel they have control over**
- **They feel good about**
- **They can do well**
- **They do voluntarily**
- **Provide security, inclusion, and affection**

What is an activity? Anything can be an activity, including personal care and chores, if you're doing it together

Definitions:

- **Activities** – The things we do.
- **Ability** – What a person can do
- **Failure-free activity** – An activity that cannot be done incorrectly. The purpose is to have fun, socialize, and be involved in the process.

Activities should

- First of all, be interesting
- Encourage socialization
- Help the person feel useful and maintain independence for as long as possible
- Be fun and enhance quality of life
- Make the best of remaining abilities and encourage creativity
- Help to reduce challenging behaviors, because the person is doing something she enjoys
- Provide intellectual stimulation

Not every activity has to meet all of the above criteria.

When choosing an activity, consider

- **The person with memory loss**

- **The activity itself**

- **Your approach – Be positive, calm, realistic and flexible. Do not criticize or correct**

Structuring the Day

When planning activities for a person with Alzheimer's, think about how you organize your own day:

- There are times you want variety and times you welcome routine.
- You want activities that provide meaning, purpose, and pleasure.

People with Alzheimer's disease want and need the same things.

Emphasize the enjoyment.

The Best Friends Approach:

The Best Friends Approach to Alzheimer Care, by Virginia Bell and David Troxel, states the Best Friends Approach to activities as follows:

- The art of activities is not in what is done; it is in the doing.
- Activities should be individualized and tap into past interests and skills.
- Activities should be adult in nature.
- Activities should recall a person's work-related past.
- Activities should stimulate the five senses (sight, hearing, taste, touch, and smell).
- Doing nothing is actually doing something.
- Activities should tap into a person's remaining physical skills.
- Activities must (sometimes) be initiated by others.
- Activities should be voluntary.
- Intergenerational activities are especially desirable.
- Activities we think will never work sometimes do.
- Activities should appeal to the caregiver as well as the person.

- Personal care is an activity.
- Activities can be short.
- Activities are everywhere.

Also from The Best Friends Approach to Alzheimer's Care is the following list of activities by categories that the authors have found to be successful:

Personal care
- Taking a bath or a bubble bath – with laughter and blowing bubbles
- Dressing can be a fashion show
- Brushing teeth
- Combing hair
- Applying makeup and making funny faces in the mirror.
- Giving a manicure
- Eating a meal and having a conversation

Doing chores makes a person feel useful
- Gardening
- Polishing the furniture
- Folding clothes
- Drying dishes
- Raking leaves
- Cooking
- Shelling peanuts

Being with pets
- Listening to the birds sing
- Brushing a dog's fur
- Petting a friendly cat
- Feeding ducks
- Giving a person some of the responsibility for pet care

Enjoying the magic of music
- Attending a church choral concert
- Playing a favorite song
- Tapping fingers and/or toes to a pronounced rhythm
- Dancing cheek-to-cheek

- Holding a whistling contest can make everyone laugh. (If you have time, you can get a few volunteers and try this.)
- Singing familiar songs.

Reminiscing – it is a basic human need to think about the past and reminisce. You can encourage it with any of the following:

- A bottle of perfume
- Advertisements in an old Life magazine
- Old household implements such as a washing board, apple peeler, or flat iron, which may lead to humorous comparisons between then and now
- Antique farm implements
- Honking the horn of a vintage car, which may bring back memories of a first date or first vehicle
- Photo albums

Old sayings, word games, clichés, or rhymes

- Flashcards of old sayings could be prepared in a fill-in-the-blank format, creating a game. Ex: "Necessity is the mother of ________."
- Rhyming words, such as glad and sad or post and toast
- Reading classic poems – some persons might surprise you by recalling every word
- Similes relating to animals, such as "loose as a goose" or "naked as a jaybird," can bring laughter to even the most serious person.
- Naming opposites, such as up and down, top and bottom, or right and left
- Listing words related to a certain color, such as Red Sea, red sky, red flag
- Composing a get-well card together for a friend or relative
- Naming state capitals

Activities with children

- Making a Halloween mask together
- Reading stories aloud to one another
- Blowing out candles, exchanging presents, singing "Happy Birthday," and eating birthday cake can make everyone smile and laugh.
- Being with children can make it acceptable for adults to play childlike games and work simple puzzles.

- Getting hugs and kisses that children give so freely makes the person feel loved.

Enjoying quiet time

- Taking a daily walk focuses the person on a single task and is a chance to “smell the roses.”
- Taking a drive
- Watching hummingbirds can help the person connect with nature.

Engaging in spiritual activities

- Reading aloud from the Bible or other religious texts
- Listening to organ music or gospel
- Praying remains a powerful, meaningful act for many people with dementia.
- Celebrating religious holidays and continuing to attend religious services
- Seeing a beautiful sunrise or sunset can lift a person’s spirit

Recognizing old skills might include the following:

- Whistling or singing
- Dancing or clogging
- Reciting a memorized speech or poem
- Playing marbles (with a child)
- Carving a corncob pipe
- Cooking a special dish

Creating arts and crafts provides a wonderful opportunity for persons to utilize their remaining strengths and abilities:

- Drawing or painting a memory from childhood, such as a house, school, creek, or forest
- Recognizing familiar paintings in an oversized art book
- Using clay to sculpt an animal
- Assembling a mobile from objects gathered on an impromptu scavenger hunt (pinecones, leaves, feathers, etc.)
- Creating sun catchers for the windows
- Filling oranges with dried cloves to give as gifts
- Making decorations for a holiday party

Additionally, exercise is good for everyone, whether you have dementia or not.

Conclusion: "Certainly, there are many more activities that can be done with almost no materials or money and on the spur of the moment. The authors encourage the reader to take on the challenge of doing activities with knack…Remember that the Best Friends philosophy is that *the secret is not necessarily in what you do – it is the doing. Life is an activity!*"

Activity: Would You Rather…

Skills Building Exercise: Developing an Activity Plan

1. Write the name of an individual with Alzheimer's disease or a related dementia that you know.

2. Identify three things you know about this person.

3. List two needs of this person (areas where they may need some help).

4. List three abilities and strengths of this person.

5. Based on what you know about the individual, what are some possible activities he or she would enjoy?

6. Write your selections below.