Instructor's Manual

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

Have a little beach fun without leaving your classroom. Beach Ball Buzz can be as fun as you choose, depending on the questions you write on the ball. Make them related to your topic or completely frivolous and fun. You'll need a permanent marker and a fairly large blow-up beach ball that can be purchased at most discount stores.

Instructions -Blow up your beach ball. Make a list of questions you'd like your participants to answer, and write a question or two on each stripe of the ball.

Sample questions:

- What is the funniest movie you've ever seen?
- If you were a cartoon or comic character, who would you be?
- What is the worst thing you've ever tasted? Did you swallow it or spit it out?
- What one thing have you kept forever that you really should throw away?
- What's your greatest pet peeve?
- Who is your favorite person and why?
- If you were a superhero, what powers would you have?
- What was your first car and did you love it or hate it?
- Who is the most famous person you've met?
- What is *your* song and why?
- How do you celebrate your birthday?
- What is the most embarrassing thing you've ever done?

Toss the ball around the room. **Whoever catches it gives her name and answers the question under her left thumb.**

Point to make: This whole day, we'll be talking about getting to know the person for whom you are providing care. You now know a little something about each person here that you didn't know before. You also know one activity that may work with some of your care receivers with dementia.

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 are

- **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 Disease (*In Participant Workbook)*

Some change in memory is normal as we grow older, but the symptoms of Alzheimer’s disease are more than simple lapses in memory. People with Alzheimer’s have difficulty communicating, learning, thinking, and reasoning — problems severe enough to have an impact on an individual's work, social activities, and family life.

It is important for people with dementia and their families to receive information, care, and support as early as possible. To help family members and health care professionals recognize warning signs of Alzheimer’s disease, the Alzheimer’s Association developed a checklist of common symptoms. The following checklist was updated in 2009 by the Alzheimer’s Association to reflect what we know about the development of Alzheimer’s disease:

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:

When a family suspects dementia, the first step should be to determine the cause of the dementia.

A physician should be consulted about concerns with memory, thinking skills, and changes in behavior. For people with dementia and their families, an early diagnosis has several advantages**. Ask participants to name benefits of an early diagnosis.** Add any that they leave out.

- Time to make choices that maximize quality of life
- Lessened anxieties about unknown problems
- A better chance of benefiting from treatment
- More time to plan for the future

There is **no diagnostic test** that can detect if a person has Alzheimer's disease. The process involves several kinds of tests and may take more than one day.

Diagnostic tools and criteria make it possible for physicians to make a diagnosis of Alzheimer's with an accuracy of about 90 percent.

The diagnostic process will involve a primary care physician and possibly other specialists. Evaluations may include the following steps (*Participant's Workbook, bolded list only)*

- **Medical history**, which collects information about current mental or physical conditions, prescription and nonprescription drug use, and family health history
- **Mental status evaluation** to assess sense of time and place; ability to remember, understand, and communicate; and ability to do simple math problems
- **A series of evaluations that test memory, reasoning, vision-motor coordination, and language skills**
- **Physical examination**, which includes the evaluation of the person's nutritional status, blood pressure, and pulse
- **Examination that tests sensation, balance, and other functions of the nervous system**

- **Brain scan** to detect other causes of dementia, such as stroke
- **Laboratory tests**, such as blood and urine tests, to provide additional information about problems other than Alzheimer's that may be causing dementia
- **Psychiatric evaluation**, which provides an assessment of mood and other emotional factors that could cause dementia-like symptoms or may accompany Alzheimer's disease

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

Impact of the Diagnosis:

Ask: How do you think you would feel if you or someone in your family got that diagnosis? Let participants discuss how they would feel and what the impact of the diagnosis would be on the individual and on the family. (There are no right or wrong answers. In a later session today, we will talk about how this disease affects families and how that may impact family interactions with direct care providers.)

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

It is important to get an understanding of the changes that occur in a person with Alzheimer's disease or a related dementia. The following changes are mild during the early stages of the disease and become moderate and then severe as the disease progresses.

Changes in cognition

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

Changes in behavior

- Communication skills deteriorate (will discuss in Communicating session)

- 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 (will discuss in Behaviors session)

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.

Refer participants to the *Stages of Symptom Progression in Alzheimer's Disease* in the pocket of their workbooks. Discuss the stages and symptoms as time allows.

Use either of the following exercises – Starfish or Aging – and then end the session with the poem, *Look at Me,* to set the stage for the rest of the training.

Story: Starfish

A small boy was walking along a beach at low tide, where countless starfish, having been washed up on the beach, were stranded and doomed to perish. A man watched as the boy picked up individual starfish and took them back into the water.

"I can see you're being very kind," said the watching man, "But there must be thousands of them; it can't possibly make any difference."

Returning from the water's edge, the boy said, "It will for that one."

~author unknown

Point to make: As a direct care worker, you make a difference for the caregiver and for that one person with Alzheimer's disease or a related dementia.

Exercise: Aging

Items needed: Popcorn kernels, cotton balls

Each person should have a small baggie with two cotton balls and a few kernels of popcorn. Ask each participant to put a few of the popcorn kernels in each shoe and put the shoes back on. *(*Simulates bunions, corns, other common foot problems associated with aging. Alzheimer's disease and related dementias happen within the context of everything else that person is experiencing.) Then ask participants to stand for just a minute. Ask, "How do your feet feel?" Get reactions; then instruct the group to sit again.

Instruct participants to put cotton in both ears. Talk to them in a normal voice for about one minute. You could recite part of the poem Look *at Me*, read from a book, or ask Alzheimer's related questions. Then instruct them to take the cotton out of their ears, and discuss what they heard and how it made them feel. (Most people will be able to hear, but the sounds are somewhat muffled, making it difficult to understand every word.)

Point to make: Alzheimer's disease happens within the context of everything else that person is experiencing.

After either of the above exercises, end the session by reading the full poem, *Look at Me*, which sets the tone for the rest of the training **- focusing on the whole person, not just the disease.**

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

(You'll need one volunteer who is willing to be blindfolded, one volunteer who thinks he/she is good at giving directions, and a third volunteer to be Neptune – and do nothing.)

After the first volunteer is blindfolded, ask "Neptune" to go to any spot in the room, stand still and remain very quiet. Second volunteer is then instructed to give blindfolded volunteer directions "to get to Neptune." Tell volunteer that he/she can give any directions but cannot touch the blindfolded volunteer. Once blindfolded volunteer "gets to Neptune," thank volunteers for being such good sports and ask participants if there is anything they would have done differently. After any discussion, make the following points:

- **Wouldn't it have been easier if he/she could have touched the blindfolded person?**
- **What if one of the directions had been "take off the blindfold?"**
- **Sometimes, we make communication more complicated than it needs to be. As caregivers, we must be creative and change how we communicate with those who have dementia.**

Alternate beginning for very small group: Read *The Bath and the Bucket*

A group of businessmen was being given a tour of a mental hospital. One of the visitors had made some very insulting remarks about the patients. After the tour, the visitors were introduced to various members of the staff. The rude visitor chatted with one of the security staff, Bill, a kindly and wise ex-policeman. "Are they all raving loonies in here then?" asked the rude man.

"Only the ones who fail the test," said Bill. "What's the test?" asked the man.

"Well, we show them a bathtub full of water, a bucket, a jug and an egg-cup, and we ask them what's the quickest way to empty the bath," said Bill.

"Oh I see, simple. The normal ones know it's the bucket, right?"

"No, actually," said Bill, "the normal ones say pull out the plug. Should I check to see if there's a bed free for you?" *~author unknown*

Source: www.BusinessBalls.com

Point to make after the exercise or the story: Sometimes, we make communication more complicated than it needs to be and ignore the obvious.

One 1970'sresearch study showed that only seven percent of communication is verbal; 38 percent is via tone; and 55 percent is non-verbal. A more recent study has shown that it may be closer to 50/50, but even at that, the power of non-verbal communication is at least as important as the words we speak. For the person with Alzheimer's disease or a related dementia, as the disease progresses, the unspoken language of the body and tone of voice may become more important than the words we use.

Anyone who comes in contact with an individual with Alzheimer's disease or a related dementia has the ability to impact that person either positively or negatively. Always keep your focus on the **PERSON** with whom you're trying to communicate – be **p**ositive, **e**mpathetic, **r**espectful**, s**incere, **o**pen, and **n**on-judgmental. (List on a flipchart or blackboard to spell out the word *PERSON* vertically.)

What if you were that person?

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? Let's face it – we all prefer that things be done a certain way. We have our likes, dislikes, idiosyncrasies, and peculiarities. These are the things that make us who we are. So, the better we, or someone acting for us, communicates these likes and dislikes to the people who will be caring for us, the better care we should receive. Please indicate below what you would **most** want the person providing care to know about you :

____

____

____

Then complete the following statements (*Go over as many as time allows, giving everyone in the group a chance to answer and pointing out how individualized our likes and dislikes are.*):

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: (Please use examples whenever possible. It can be stories you heard when you took the training or examples of your own.)

Everyone is different.

- Look around the room. We're all different, and if we all got Alzheimer's disease today, we would each progress through it differently.
- If you've seen one person with Alzheimer's disease, you've seen one person with Alzheimer's disease.

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

- It's important to separate the person from the disease.

- The individual's behavior, however difficult it is to deal with, is a result of the disease.
- Try putting yourself in that person's place. If you were experiencing memory loss and confusion, don't you think you might be rather difficult, too? **How would you react to the frustration?**

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

- **Reality orientation, reasoning, rationalization, and logic do not work for most people with Alzheimer's disease.**
- Her reality is "right now." As the disease progresses, she may be unable to plan for tomorrow, so there is no future. She may not remember what happened yesterday, so there is no past. There is only now. "Right now," though, in her reality, may be when she was sixteen or thirty-five or…
- If recent memory is impaired, reality is somewhere in the past. That reality may change from day to day.
- Acceptance of her "reality" as part of the person with dementia is an important part of communicating with the individual.
- It's easier and more productive to go to her reality than to try to get her to come to yours. Jolene Brackey, who wrote <u>Creating Moments of Joy</u>, called it "living in their truth."
- There is a sense of connection when a person tells a story, even if she is altering the truth.

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

- Have you ever talked to someone you knew wasn't listening? How did that make you feel?
- Remember, you are both trying to understand each other, but most of the burden for understanding is on <u>you</u>.
- Encourage the person to continue to express thoughts, even if she is having difficulty or you don't understand.

Focus on feelings, not facts.

- Ask yourself, "In this situation, whose truth matters?
- If <u>your</u> truth doesn't matter, then focus on the <u>feelings</u> expressed in her truth.
- **Reality orientation does not work for individuals with dementia and can be very frustrating to them. (Repeat)**

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

- Focus on what she can do now.
- For most people, being is doing. Let the individual do as much as possible for as long as possible.
- It doesn't matter if the individual performs the task correctly. What does matter is whether she enjoys the activity or becomes upset because she can't do something as well as she could previously do it.

Prepare the person for what's about to happen.

- Too much advance notice will likely lead to repetitive questions about the event.
- No notice or explanation may cause the person to be anxious or resistant.
- It may be difficult to strike a balance between the two. You need to try.

Assume the person understands everything you say.

- It's rude to talk about someone as if she's not there.
- She probably doesn't understand everything you say, but we don't know how much an individual with Alzheimer's comprehends, especially if she can't communicate a response back to us.

Be realistic; be patient.

- An individual's abilities will change over time. Adjust your expectations accordingly to avoid frustrating the person with dementia.
- Encourage the person to take her time. How do you react when you feel rushed?
- Since it takes longer for him to process what you say, it will take longer for him to respond. Patience is, indeed, a virtue when you are caring for someone with Alzheimer's disease!

Don't argue, criticize, correct, or reason.

- These are the ways we normally communicate.
- **You will never win an argument with someone with Alzheimer's disease.**
- Avoid using negative statements and quizzing. (Ex: You know who I am, don't you?)
- Arguing, criticizing, correcting or reasoning will produce a lose/lose situation – the individual will get frustrated; you'll get upset; everybody loses.

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

- If you know enough about the person for whom you're caring, you should know one or two things you can suggest to distract her that will diffuse a potentially difficult situation.
- If you have the luxury of time, wait 10-15 minutes and try again. You may get a completely different response.

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

- People with dementia do and say funny things, just like the rest of us.
- As long as you are laughing <u>with</u> someone with dementia and not <u>at</u> her, you should both just enjoy the moment.

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.

- Sometimes it's better to do nothing than to do something that may provoke unwanted behaviors.
- The big <u>if</u>, though, is whether you can put up with it and for how long.

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

- Some words may no longer have meaning to the individual with Alzheimer's disease. Other words may not register.
- With a shorter attention span, she may not be listening to every word you say.
- What happens when people aren't listening to every word you say? (They may "hear" something totally different than the meaning you intended.)

An Exercise in Understanding:

Take time here to have a little fun and play a game of "Gossip." Give one person at the front of the room the following sentence in writing:

The city dude and the country spouse lived together in a cute little house that had an animal theme for each room, including a living room with horses, a bedroom of birds, cows in the kitchen, and lambs in their baby girl's nursery.

Ask that person to **whisper** the sentence to the person next to her. Each one whispers exactly what he/she hears to the next person until it reaches the other end of the room. Ask the final person to repeat what she heard. Then read the original sentence to the group.

Points to make:

- **Reiterate the point that what you say may not be what she hears.**
- **Did you notice how much shorter the sentence got as it was passed along? If we can't remember long sentences or instructions, how can we expect someone with dementia to do it?**

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.

- Make sure to call the person by the name he/she prefers.
- Identifying yourself is a common courtesy, and it may help to put the individual at ease.

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

- **Break all tasks down into simple steps, using short, easy to understand sentences.** *(*We will discuss this further during the Behaviors Session)
- **Give the individual adequate time to respond.** Remember, time doesn't mean the same thing to someone with Alzheimer's that it does to you and me. It takes longer to process what you say and longer to respond.
- **If you have to repeat something, use the same words**. If you rephrase, you force the person to begin processing all over again. If repeating doesn't work, wait a few minutes, and try again, using different phrasing.
- **Be prepared to give the information more than once.** It may not register or be understood the first time or even the second.

Keep it simple.

- **Emphasize key words; listen for key words**. Both of you are trying to be understood, but it's up to you to do most of the understanding.
- **Ask family members about possible meanings for words, names, or phrases that you do not understand.**

- **Avoid open-ended questions**. Help the individual to make a decision by limiting choices to yes-no or either-or (Two shirts, two dresses, two food choices).
- **Avoid pronouns as much as possible**. Name the object or person.

Put the emphasis on the person.

- **Use the person's name frequently to keep her focused.**
- **Validate responses and feelings**. Remember that you are "living in her truth," not yours. Give her a chance to tell you about whatever is bothering her. (For example, if she says, "I want to go home," you could ask her to tell you about her home – where it is, what she likes best about it, the neighbors, etc.)
- Ask participants how they would validate the following statements:

> **"My daughter never comes to see me." (And you know she's there regularly.)** Examples: Tell me about your daughter. What was she like as a child? What color is her hair? Do you have other children?
>
> **"I know you stole my purse, and I want you to leave."** Examples: When did you see it last? What color is it? Where do you usually keep it? Would you like me to help you find it?

- **Show respect**. Even though behaviors may be childlike, this is a person with a long history, who deserves to be treated like an adult.

Non-Verbal Communication

Demosthenes lived in the fourth century B.C. and is regarded as the greatest Greek orator. When he was asked what was the first part of oratory he answered, "'action;" and which was the second, he replied, "action;" and which was third he still answered, "action." Demosthenes felt strongly that people tend to believe actions more than words. And we still hear that today: Actions speak louder than words. **What do you think? When a person's words and actions don't match, which are you more likely to believe? Why?**

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**. Keep it positive, soothing, calm. You can say the sweetest things, but if your tone is brusque or angry, that's what the individual with Alzheimer's may hear.

Your approach

- **Approach the person slowly and from the front.** If you've ever been startled from behind, you can understand how someone with dementia might respond.
- **Make eye contact, and maintain it as much as possible**. If there are distractions, the person with dementia may not know who or what to focus on. Maintaining eye contact helps to keep him focused on you.
- **Use physical touch to calm the individual and to keep her attention – hugging, patting, stroking, holding hands, etc.** Note: Know the individual! If it's someone who responds badly to being touched, then you need to know that and act accordingly. Patting, stroking, hugging, or holding hands can be very effective for you and meaningful to the individual.
- **Eliminate background noise as much as possible.** Since focus and concentration can be difficult to maintain, anything you can do to eliminate distractions may be helpful.

Touch activity

Divide attendees into groups (or have them stand when the level they're comfortable with is discussed) according to how much touching they're comfortable with – **minimal –** shake hands or hold hands, **moderate –** pat on the arm or half hug, **maximum –** full hugs (all the touching you can get). Ask the groups to answer the following questions:

- Why do you think you're comfortable with the level of physical contact you've indicated?
- How do you feel when the touching is out of your comfort zone?
- What would it take for you to be comfortable with more physical contact?
- How would you feel if you had no human contact?

If you're caring for a person with dementia, why is it important to know the kinds of touch you can use to make a person the most comfortable?

- Wrong form of touch could trigger an overreaction.
- You could find out he doesn't like to be hugged with a left hook.
- If she's uncomfortable, she's less likely to be cooperative for ADL's, etc.

Take advantage of the power of body language, expressions and gestures!

- **Be calm and supportive.**
- **Maintain a relaxed posture**. If you are tense, angry, frustrated or bored, it can show in your body posture.
- **Be aware of facial expressions**. You may be saying one thing, but your expression may be telling the person with Alzheimer's something totally different. One very effective way to communicate with people who do not understand what you are saying is to **smile.** More often than not, they will smile back, and you've made a connection.
- **Use gestures to help convey your message.** Gestures can be used alone or in conjunction with words or facial expressions to make your message as easy to understand as possible. Sometimes, the most important non-verbal communication tools you have are your hands, and gestures are your most important means of communication. (**Take a minute, and ask participants to guess the meaning of the following gestures to show how much we can communicate without using words:** stand up (*repeat the gesture until everyone is standing)*, yes, no, turn around, permission to speak, stop, be quiet, call me, goodbye, peace sign, come here, okay, sit down).
- **Get low, and go slow.** As much as possible, get down to eye level with the person, and don't appear to be rushed, even if you are.
- **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.** Discuss the following questions briefly:
    - Do you dress differently at home than you do for work? Why?
    - Do you plan what to wear for different occasions? If the answer is yes, then you are planning the message you want to convey.

    - What do seniors think of how we dress? Do you think it influences their acceptance of persons who go into their homes?
    - Do any of you have a dress code for direct care workers?
- **What you wear sends a message, whether you intend it to or not.**

Colors. For seniors in general, and particularly for people with Alzheimer's disease, think *contrast.* (Show color wheel at this time, and point out the difficulty in distinguishing colors that are next to each other and how much easier it is to see the difference in colors that are far apart on the spectrum.) For families, this may mean making sure the plate is a different color than the tablecloth or the commode different from the floor or rug.

Please keep in mind that no single gesture or other form of non-verbal behavior by itself should be considered an indication of *anything.* Consider groups of messages, and put them in context. (Ex: A fist pump would be inappropriate at a staff meeting but perfectly appropriate at a basketball game).

The people for whom you provide care receive messages from you. Make sure your message is positive and conveys the message you intend. People are sending you messages. Sometimes, you have to be very alert to understand what a person is communicating to you, especially when it's someone who has difficulty putting thoughts together verbally.

Activity: Group charades

Divide everyone into teams of 6-8 people per group. Have each team draw an index card on which you have written a word. Give the teams 3-5 minutes to figure out how to demonstrate to everyone what is on the card. All members of the team must participate. Each member of the team can have a separate part in the demonstration, or all members can participate doing exactly the same thing. It's up to the team to figure out the best way to communicate their word **without talking.**

They have to work together to decide how to make it clear to the rest of the attendees. Then each team will come to the front of the room and non-verbally communicate their word. So that you will know when they have finished, ask each group to bow at the conclusion of their demonstration. If someone from the audience hasn't already said the word, ask if they know what it is.

Words you can use include *water, house, flag, table, paper, pantyhose, TV, comforter, office, printer, bubbles, or tree,* or you may come up with other words.

If time allows or if you have a very small group, use the following skills building exercise:

Verbal and Non-Verbal Communication Techniques

Divide the group into three teams for the scenarios that follow. If you don't have enough participants for three groups, decide which scenario(s) you want to use and divide the group accordingly. (Scenarios are included at the end of the Communicating Session in the Participant Workbook.) Assign a scenario to each group, or, with a very small group, pick one scenario that you want them to read and discuss. Then instruct them as follows*:* As a group, discuss your assigned exercise. Decide what you would do, based on the handout, *Stages of Alzheimer's Disease,* and lessons learned in this communicating session. Be prepared to answer the questions at the end of your scenario.

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

Get everyone up out of their seats. Tell them you want them to line up in different orders. Don’t give them any more rules or guidelines than are mentioned below. Let them figure it out and solve the problem. You can use any or all of the following:

Street address/P.O. Box number
Height
Color of shirt or top (lightest to darkest)
Hair color (darkest to lightest)
Birthdays

Have the group do one of the above non-verbally. Height, color of shirt or hair color would work.

Point to make: Understanding behaviors is problem-solving. The more information you have and the better you get to know a person, the more likely it will be that you can figure out the reason for a behavior and adjust your actions accordingly. Take time to get to know the person for whom you are providing care.

Alternate Beginning Exercise (can be used with any size group, even very small)**:**

Ask participants to pair up with someone they don’t know and find some things the two of them have in common that are not related to work. Give the pairs approximately three minutes, and then ask each pair to quickly report what they found out about their shared interests and experiences.

Point to make after the exercise: As a direct care worker, you are going to be much more comfortable with the person for whom you are providing care, if you take a little time to get to know her and let her get to know you. Additionally, to understand why an individual reacts or behaves in a certain way and to provide the best care possible, it is essential that you know as much about that person as possible.

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 –** General unrest, uneasiness or apprehension. It covers a broad range of behaviors that may change as the disease progresses and may include pacing, nervousness, handwringing, shouting, screaming and throwing objects. Agitation is usually not directed at a specific person.
- **Aggression –** Behaviors may include those listed for anxiety or agitation, plus hitting, pushing or verbal threats, any of which may occur when a caregiver attempts to help an individual with daily activities. Aggressive individuals may cause harm to others or to themselves.
- **Wandering –** The most common behavior in people with Alzheimer's disease. The dictionary describes wandering as "moving about with no definite destination or purpose." People with dementia who wander *do* have a purpose, either trying to get **to** something or someone or attempting to get **away** from a situation or someone.
- **Suspicion/paranoia** – is also common in Alzheimer's disease, as memory becomes progressively worse. It is often exhibited when an individual misinterprets a situation or believes something belonging to her has been taken.
- **Delusions/hallucinations –** Misperceptions. A delusion is a false, fixed belief that remains despite all evidence to the contrary. A hallucination is a false sensory experience, seeing something that does not exist and believing it is real.
- **Sleep disturbances –** Can occur throughout the course of the disease and may include sleeplessness, having days and nights reversed, wandering at night, and sleeping more as the disease progresses. Sleep disturbances may accompany many of the other behavioral symptoms listed.
- **Inappropriate sexual behaviors** – Sexual behaviors that are dysfunctional, serve no useful, healthy purpose, or do not fit within the setting. Sexual

desires and feelings of individuals with Alzheimer's disease may remain intact, while their ability to express those feelings and use proper judgment is impaired. As direct care workers, it may be up to you to determine if the behavior is actually sexual, if it's appropriate, and whom it embarrasses. Then you can determine an appropriate response.

We will discuss ways to respond to challenging behaviors later in this session.

Why behavior challenges occur:

- **Other health conditions that affect behavior –** Includes impaired vision or hearing, an acute illness, a chronic condition, dehydration, or constipation. How would you react to any of these conditions?

- **Pain/discomfort:** Just like the rest of us, people with Alzheimer's or a related dementia may have other health problems that affect behaviors. **As a first step in reducing challenging behaviors, assess for pain and discomfort.** If the person has lost the ability to verbally communicate, it is up to us to find a way to assess the type and level of pain or discomfort.
  - Pain is the most common symptom of many chronic diseases in older adults.
  - More than two-thirds of persons in nursing homes indicate the presence of pain at least some of the time.
  - You cannot dismiss a complaint of pain, even if the person later forgets she reported having the pain.
  - Individuals with Alzheimer's disease usually have other medical diagnoses, too, such as diabetes, COPD, arthritis, headaches or chronic back pain.
  - Anyone providing care for an individual with Alzheimer's needs to be made aware of that person's pain history. *Imagine for a minute that you are the person with dementia.* Do you have any kind of chronic or recurring pain – headaches, bad knee, kidney stones, arthritis, or some other chronic condition that wouldn't be visible to the worker caring for you? How cooperative would you be if you were in pain and couldn't communicate it to the person providing care?
  - Sometimes, relieving the discomfort may be as simple as adjusting her bra, making sure his pants aren't too tight around the waist or helping her change into her favorite slippers. *Think about how cranky you get if your clothes or shoes are uncomfortable.*

- **Effects of medication –** People with Alzheimer’s disease are more vulnerable to the side effects of medications, overmedication, and reactions to combinations of drugs.
- **Depression** – Difficult to diagnose in people with dementia, because symptoms commonly associated with depression – apathy, withdrawal, loss of interest in activities – are also symptoms of dementia. It may also be difficult for individuals to describe the sadness and hopelessness they feel. Up to 40% of individuals with Alzheimer’s disease also suffer significant depression.
- **The environment –** It may be **confusing** with no cues to help the person with Alzheimer’s know where to find things or which way to go (example: Not knowing how to find the bathroom). The space may be **overwhelming** – too big or too much clutter or it may be **unfamiliar**, a new place the person has never been or a once familiar place she has now forgotten (example: a new restaurant).
- **Excessive stimulation** – Too much going on at one time – music, conversation, too many people, other noises. The person with Alzheimer’s may be easily distracted, not know where to focus her attention, or become agitated.
- **Unstructured environment** – People with Alzheimer’s disease and related dementias need a certain amount of structure and daily routine. Too little structure may cause the person additional stress. However, it can’t be a rigid schedule; there needs to be flexibility built in. **Have a plan, but be ready and willing to change it.**
- **Poor sensory environment** – As we age, the ability to see, hear, feel, smell and taste changes. One or more of these senses is usually impaired in people with Alzheimer’s disease. If you’ve ever had even a momentary disruption in one of your senses, you know how it can affect your ability to function (examples: glare from sunlight while you’re driving, trying to tie or untie your shoes with gloves on, tasting food when you have a bad cold).
- **Visual/spatial skills** – For some people with Alzheimer’s, there’s a visual/spatial deficit. The floor or bottom of the bathtub may appear farther away. Judging distances can become an issue (the person may miss the chair or toilet seat). She may not step on dark carpet or rugs, because they appear to be dark holes. For some, there’s even a visual/spatial deficit that makes what a person sees appear to be in still pictures, rather than the moving scenes we all see before us.
- **Communication may be difficult** – Many of us become frustrated, agitated and even angry when we don’t know what is expected of us or when we

can't make ourselves understood. It shouldn't be surprising that people with Alzheimer's react in similar ways. When two or more people interact, each is trying to understand the other. As we said in the Communicating Session, when a person has dementia, more of the responsibility for understanding and being understood is **yours**.

- **The task itself (what you're asking the person to do)** – May be **too complicated or too many steps combined.** It may be difficult for the person to figure out the **sequence of steps** necessary to complete the task. Tasks need to be modified as the person's ability to function declines.

Use one or both of the task exercises below.

Task related exercise 1:
Have everyone take 2-3 minutes to write directions for someone to follow when brushing her teeth. Ask some of the participants to tell you how many steps they wrote down. (You can tell them here that someone determined that there are more than seventy steps!) What we think of as a simple task may seem complex to someone with dementia.

Also, if the **task is unfamiliar**, the person may not be able to do it. People with Alzheimer's disease gradually lose their ability to learn new skills. Focus on tasks the person may have learned long before the onset of Alzheimer's – washing dishes, making the bed, gardening, raking leaves, tinkering with the car, folding laundry, etc. **Knowing the person's personal history will help you to provide the best care possible.**

Task related exercise 2:
Stop here to try a very familiar task – **making a peanut butter sandwich** (from Karen Stobbe's "In the Moment" training). Have all of your supplies in front of you – new jar of peanut butter, napkin or plate, dinner knife (not plastic) or spreader, loaf of bread, and paper towels or damp cloth to wipe your hands off afterward. Invite participants to gather in front of the table where you will make the sandwich. (It's an opportunity for participants to get out of their seats and move around a little bit.)

Simply state:
"I am going to make a peanut butter sandwich, and I would like all of you to tell me how to do it. I will try to listen to and interpret your instructions as though I have Alzheimer's disease."

You may have to prompt people to get them going. Usually, the first instruction is to open the loaf of bread by untwisting the tie. By continuing to twist it, you can make the tie tighter, no matter which direction you're twisting. Eventually, someone will probably get frustrated and suggest that you just tear the bag open. Do it. Even if it's not suggested, show some frustration and tear the bag open. Keep going, taking their instructions literally. You can pick up the knife at the wrong end, pick up the peanut butter while you're still holding the knife, or appear to be very confused at all the instructions coming at you at once. Just think how someone with Alzheimer's disease might interpret the instructions. Always use a new, sealed jar of peanut butter. As you keep trying unsuccessfully to open the seal, you will probably have participants who just want to do it for you, and someone will strongly suggest that you just stab the seal with your knife. Do it, and make enough of a hole that you can get peanut butter on the knife through the hole. Keep taking directions, and don't stop until you have made a sandwich.

Points to make after the exercise:

- **A person with Alzheimer's disease has the right to do as much as possible for as long as possible. If it does not seem to be too frustrating for her, she should be encouraged to continue, even if it's exasperating for us.**
- **The person needs the right instructions and needs to have them broken down into steps she can understand.**
- **Did anyone use your name while they were giving you instructions? If so, acknowledge that person – good job. If not, make the point that participants should have said your name to help keep you focused.**
- **Did anyone give you praise when you did something right? If so, acknowledge that person. So often, with Alzheimer's disease, we focus on what the person *can't* do. We need to praise and focus on remaining abilities.**

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? *The resident became upset and wouldn't eat.*
   What happened before the behavior? *She didn't get her check.*
   What were the consequences of her behavior? *The staff got creative and found a way for her to be "paid" for the work she thought she still did.* You can stop here to ask what might have happened if the staff had continued to try to convince the resident to eat but hadn't done anything about her "check." The consequences could have been entirely different. **Make the point again that her reality is different from ours and if there is a problem, we need to find a solution that makes sense to her – and a solution that preserves her dignity.**

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? *He was yelling.*
What happened right before the behavior? *He saw the worker and his wife talking– and didn't know what they were saying.*
What were the consequences of his behavior? *The man was comforted, which showed that they were concerned about him. However, he was comforted for* ***yelling****, so he may repeat that behavior. There's nothing wrong with what the worker and the man's wife did. Just keep in mind that you should provide the warmest reactions when he remains calm and is being more cooperative.*

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. In fact, you could use the same ABC method to assess your behavior as a direct care worker:

A. What happened right before the behavior? *The person with Alzheimer's was angry, agitated and yelling.*
B. What was your behavior? *You reacted angrily and yelled at him.*
C. What were the consequences of your behavior? *The situation got worse; the person became even more agitated; and now he is also combative.* **You have a bigger problem.**

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

Note: Not every behavior is a problem. It may just be irritating, and most of us do things that irritate other people. If a behavior does not cause a problem for the person with Alzheimer's, for others or for you, the best strategy may be to do nothing.

When there *is* a behavior issue that has to be addressed, one or more of the following recommendations may help:

1. **Get to know the person before trying to assist with ADLs or other tasks**. If she likes you, she will probably be more willing to do what you're asking her to do and even let you help, if necessary.

2. **Have a diversion or way to redirect the person's attention in mind before there's a problem with a behavior.** Know at least one or two things you can suggest and do together that would divert her attention to something she enjoys.

   Example: While talking about the good old days, Mrs. Smith becomes anxious and wants to pace. Walking with her and talking about the beautiful flowers in the room or a picture on the wall or asking a question about a pleasant memory from her past may help her calm down.

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

   Examples: If there are too many people in the living room and the noise level is more than she can tolerate, take her into the kitchen for a cup of coffee or piece of pie – or both. Change the channel or turn off the TV if a program is causing him to become agitated.

4. **Break all tasks down into smaller and simpler steps.** This is most commonly used in daily care/self-care activities but can also be used for recreational activities or eating (making a peanut butter sandwich, for example).

5. **Don't rush the person or act like you're in a hurry.** How does it make you feel when someone is rushing you to do something faster than you're capable of doing? **Encourage the person to do as much for himself as possible, but give help *before* the person reaches a point of frustration.** Never take over an activity just because the person is slow and you are frustrated.

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

   Example: Set two pair of pants and two shirts on the bed, and let the person choose what she wants to wear. More than two choices (the entire drawer or closet) can be overwhelming.

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

   Example: Increasing the level of light indoors as the sun is setting helps many individuals who typically experience increased agitation at this time of day to remain calmer and be less disoriented. (Late afternoon and evening agitation is referred to as sundowning. Often, it happens when there are more shadows and less light in a room.)

8. **Give her reassurance, and provide a sense of safety and security**. This is most effective when fear and anxiety are the root cause of the behavior. Give encouragement – freely and frequently. We all need reassurance, and people with Alzheimer's disease need it even more. For many people with Alzheimer's or a related dementia, just having someone there provides a sense of security.

   Praise for small successes – *when they happen.* Give compliments as soon as they are earned. If you wait, the praise may have no meaning to the person with dementia.

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

   Example: You must do all you can to prevent a person from walking onto a busy highway or away from a facility.

Setting limits/saying “no” should be used when other interventions have not worked. **Taking control** of the situation should be the choice of last resort, when the person is at immediate risk of injury to himself or others.

10. **Respect the person’s privacy and level of modesty.** What she feels is appropriate may be different from what you think is appropriate. Respect her choices to the extent possible, especially if you are assisting with bathing, dressing, toileting or any other up-close-and-personal service.

11. **Do not keep the individual waiting**. How does it make you feel when someone keeps you waiting? Have everything you need ready in advance.

12. **Establish a plan and a routine based on preferences of the individual.** How would you like it if someone determined your routine every day? Wouldn’t you hope that person would at least take your likes and preferences into consideration? People with Alzheimer’s disease do like a routine, and you do need a plan for the day, but don’t be rigid with it. It’s okay to suggest something new or different. If there’s no interest or the person becomes agitated, then go back to what’s familiar and comfortable. At times, *you* may even learn a new talent or skill. Be open to that.

Examples: FAIR workers have learned to crochet, make cornbread from scratch, plant a small garden and find bargains at a flea market, all because that’s what care receivers with dementia wanted to do, and they couldn’t do it by themselves.

Skill Building Exercise: You Are Unique

State: We’ve mentioned several times today the importance or getting to know the person for whom you are providing care and the uniqueness of each person. Each of us has likes and dislikes that are similar to other people’s likes and dislikes, but we also have traits, skills, preferences and peculiarities that are different from others. All of those things together are what make you *you*. Let’s try an exercise that may demonstrate some of our similarities and our differences.

Give each person an index card, and ask each one to write the following on the card: On the top left of the card, write the words ***I am a.*** At the bottom of the card, on the right, write the word ***person.***

Have everyone stand, take their index card and a pen or pencil, and gather in one part of the room. Then give the following instructions to the group:

I'm going to give you two words, and you need to make a choice between those two words. You must choose which one you prefer, even if you don't have much of a preference for either. For instance, I will say ***chocolate*** *and point to the left and* ***vanilla*** *and point to the right. Everyone who prefers chocolate would move to my left, and everyone who prefers vanilla would move to my right. Then write your preference, chocolate or vanilla, on your index card. I will then give you two more choices and indicate where to move in the room. Make your choice; move to that part of the room; and write your preference on your card. Each time, you make a choice between two options; move to that part of the room; and write your preference on the card. Okay, let's try it, and we'll start with chocolate over here (point to the area you want them to go) and vanilla here (pointing to indicate the area). Then remind them to write the word on their card; give them a minute to do so; and then move on to the next set of words.*

After you have gone through the list below (and you can add more sets of words if you want), have everyone go back to their seats, and ask a few volunteers to read their cards. It should go something like this: I am a chocolate, mountains, TV, seafood, cat, toilet paper over, night person, pie, dancing, late, shower, WVU person.

Ocean or mountains
TV or book
Steak or seafood
Cat or dog
Toilet paper over or toilet paper under
Morning person or night person
Cake or pie
Dancing or singing
Prompt or late
Bath or shower
WVU or Marshall

Emphasize once again that

- **Each of us is unique.**
- **We all have similarities, and we all have differences.**
- **We cannot inject our own preferences onto someone else.**

- **How a person responds to a situation depends on many factors.**
- **The more we know, the better we can understand why different people react differently to the same situation.**

Ten minute break

Session IV

Working with Families

Working with Families

Beginning Exercise #1

If you have a very small group:

Prior to the training, purchase or borrow one 24-piece puzzle. If you have a larger group, use more than one puzzle. Give each person one piece of the puzzle (the more non-descript it is, the better).

> Ask: With the piece you have in your hand, how much do you know about the puzzle? Answer: **Not much.**

If you have any remaining pieces of the puzzle, put them on a table. Invite participants to take their pieces to the table and put the puzzle or puzzles together.

> Ask: What did it take to complete the puzzle?
> Answer: **Having all of the pieces and working together.**

If you have a larger group, use more than one puzzle, and follow the above procedure.

Point to make: Providing quality care for an individual with Alzheimer's disease or a related dementia requires getting to know as much as you can (having as many pieces of the puzzle as possible). It also means working together, involving the individual when possible, the family, provider agency , direct care worker and any other agency or organization providing services to that family.

Exercise #2

Ask each person to assume the role of a family member – an adult child, the spouse, a teenager, or sibling of the person with the disease. Explain that you are going to discuss changes in the person with Alzheimer's disease and ask them to consider how those changes would affect the family member that each participant has chosen to be. Then state:

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. (As you name each change or loss, ask participants to discuss how it would affect the family members they have chosen to role play.) 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 <u>Alzheimer's: The Complete Guide for Families and Loved Ones</u>:

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

- It's a natural reaction.
- It can create family conflict when one or more family members are in denial.
- It can prevent the family from seeking help. If one or more family members insist that nothing is wrong, they will not be willing to talk about how they can help or the need for outside assistance.

How you can help: You can't <u>make</u> someone accept the reality of Alzheimer's disease. Finding out that a loved one has Alzheimer's or a related dementia can be devastating, and denial is one way of coping. You can provide accurate information when appropriate, and you can listen without judging.

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

- This is a caregiver trying to be superwoman or superman.
- It is sometimes difficult for caregivers to realize they are doing too much when they are just doing the best they can to get through each day.
- As with denial, this can create a barrier to getting help.

How you can help: Agree with the family member that providing quality care is a priority, while gently making the point that she doesn't have to do it alone. Assure the over-involved family member that feelings of guilt, loss and anger are normal and that asking for help is a sign of caring and strength, not weakness.

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

- It may be directed at the person with Alzheimer's disease, at the caregiver herself, at the worker, or even at God.
- It can result from feelings of frustration, exhaustion, and loss, or from embarrassment at the individual's behavior.
- Getting so angry can cause feelings of guilt.

How you can help: Listen without judging. **Emphasize that it's okay to direct anger at the *disease* but not at the person.** Encourage the caregiver to find ways to take some time for herself.

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

- Old conflicts that were never resolved
- Wishing for the individual with dementia to die
- Making tough decisions

- Feeling like you haven't done enough (being under the impression that if you just did more, your loved one would get better)
- Taking time for yourself

How you can help: Learn more about guilt and how it can affect families of individuals with Alzheimer's disease. If the family member's guilt persists and affects the decisions she makes, she may want to consider counseling.

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.

- It is difficult to get all family members to accept the realities of Alzheimer's disease at the same time.
- Even those who understand and accept the disease and its progression may revert to earlier stages of adjustment when there is a crisis or difficult decision to make.

How you can help: Assure the family caregiver that it's okay to take time for herself. When appropriate, ask for her thoughts on caregiving issues, and help her to accept that the person with Alzheimer's disease will have good days and bad days (just like the rest of us). The difference is you have to define *good* and *bad* based on the person's level of functioning at that time.

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

Ask participants: What causes you stress? Give participants the opportunity to discuss situations, both professional and personal, that cause them stress. List responses on a flip chart or chalk board, and set aside for later.

Major causes of caregiver stress:

- **Being overwhelmed** – Many new caregivers don't know what they need, what services are available or even how to find out.

- **When the spouse is the caregiver and the person with Alzheimer's is younger** – Both the person with Alzheimer's and the spouse may still be employed, so loss of income is a big concern. There may still be children at home, so the caregiver is "sandwiched" between the responsibilities of caring for the children and caring for a spouse. Feelings may change, as the spouse sees herself more as a caregiver and less as a spouse and partner.

- **When the spouse is the caregiver and the person with Alzheimer's is older** – Both the caregiver and the person with Alzheimer's may have other, unrelated, physical problems. Additionally, the caregiver may have to take on responsibilities that she/he has never had before. (Ex: wife responsible for paying the bills and mowing the grass; husband doing laundry and cleaning the house). As above, feelings may change, as the spouse sees herself more as a caregiver and less as a spouse and partner.

- **When the caregiver is an adult child or other younger relative –** Roles change, and the caregiver may have to make difficult decisions involving a parent's care. This is especially difficult if the parent has always been stern, and the adult child has never been able to stand up to him/her.

- **Caregiver fatigue** (pass out the Caregiver Fatigue Timeline or point it out if it's already in their packets) – Caring for someone with Alzheimer's disease can be a very long journey. It is physically and emotionally exhausting and can be financially devastating. Take a few minutes to look at the Caregiver Fatigue Timeline, and note the progression of symptoms that can result from caring for a loved one for an extended period of time. **That's one of the reasons in-home services are so important.**

- **Other family members** – Everyone wants what's "best for mom" but can't agree on what that is, and they want the primary caregiver to do most or all of it. They are willing to criticize and give advice but don't want to do their part. Additionally, if there were relationship issues with family members before one family member got Alzheimer's, it is likely to get worse, not better.

- **The uncertainty of the future** – This is an unpredictable disease that can last many years. It takes its toll on caregivers – emotionally, physically, mentally and financially.

Take a moment to compare the list above with the list on your flip chart. Caregivers also experience some of the day-to-day stresses that participants listed.

Signs of Caregiver Stress: Caregivers experience tremendous stress, which may be expressed in any of the following ways:

1. **Denial –** about the realities of Alzheimer's disease and the effect it will have on a loved one, refusing to accept that the person isn't going to get better.

2. **Anger** – at the person with Alzheimer's or others, angry that there aren't effective treatments and no cure exists, angry that others don't understand what she is going through.

3. **Social withdrawal** – from friends and activities.

4. **Anxiety** – about facing another day, what the future holds, what to do when the person needs more care than she can provide.

5. **Depression** – which affects the caregiver's ability to cope. Caregivers of individuals with dementia are more likely to experience depression than non-caregivers.

6. **Exhaustion** – which makes it more difficult to complete daily tasks, think clearly and make tough decisions.

7. **Sleeplessness** – caused by a never-ending list of concerns. Sleep is especially difficult if the person with Alzheimer's roams the house during the night or is at risk to wander and become lost.

8. **Irritability** – and moodiness, which trigger negative responses and reactions. That can lead to arguments with the person with Alzheimer's, and we already know that nobody wins when that happens.

9. **Lack of concentration** – Makes it extremely difficult to focus on what you have to do.

10. **Health problems** – begin to take their toll physically, mentally and emotionally.

Give each participant the *Results of Stress* handout, or if it is in their training folder, have them get it out.

Then ask and discuss: How do you handle stress? What do you do to relieve stress?

There's a book by Sue Salach, titled Just When U Think U Know What You're Talking About – Along Comes Grandpa! At the time she wrote this book, Ms. Salach had worked in the geriatric health care field for more than fifteen years in various settings, including nursing homes, hospice education and geriatric care management. The book provides resources for caregivers. It is also painfully honest about how difficult it can be to provide care for a loved one. 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** – You'll get frustrated and disappoint others.
- **Learn as much as you can** – Just as with any job, you need to be as prepared as possible.

- **Prepare for appointments and take notes** – have your top three questions ready, and get them answered. You have to be an advocate as well as a caregiver.
- **Learn how to say no** – It is better to say no than to commit to more than you can possibly do.
- **Get over being embarrassed by your loved one -** If your loved one has Alzheimer's or some other dementia, chances are the filter that says "no, no, don't say that" is gone. So you should expect your loved one to say things that may be blunt and direct.
- **Have a schedule/be flexible** – Persons with Alzheimer's disease like a routine, but don't make it too rigid. Provide as much flexibility and choice as possible. Sometimes, the interruption may be the best part of your day.
- **Schedule some "me" time** – Many caregivers feel that taking time for themselves is selfish. It **isn't**. It renews you, relaxes you and allows you to continue providing care with a better attitude and more energy.
- **Don't be afraid to get silly -** Did you know that your body doesn't know the difference between real laughter and fake laughter? It releases the same endorphins. So, make yourself laugh, until you have something to really laugh about. Caregivers need to be encouraged to let go, laugh and have a little fun whenever and wherever they can find it. (By this time, participants may need an opportunity to let go a little, too. Give everybody, including yourself, at least two regular sized marshmallows. Talk about all the things you can do with marshmallows – melt, roast, squeeze, eat. Then throw one of them at someone and the other one at another person. Tell participants to fire away and throw their marshmallows at any other person in the room. Then pick them up and throw them again – and again. Finally, have them throw all the marshmallows toward you, so they will be easier to collect. By this time, participants are usually pretty giddy, so it may take a minute or two for them to settle down.) Caregivers may need permission to let go and have a little fun.
- **Ask for help; assign responsibilities** – Many caregivers are reluctant to ask for or accept help. If a caregiver has family or friends who are willing to help, that caregiver should be encouraged to let others help and give them specific ways they can assist.

- **Get a regular break –** That's what FAIR and other respite programs are all about – giving the caregiver a break from the responsibilities of providing care. What you do is important!
- **Deal with stress** – All of the above should help a caregiver deal with stress. Other things you can do that are specifically designed to reduce stress include deep breathing, progressive muscle relaxation, yoga, Tai Chi, massage therapy, exercise, meditation, or sensory approaches (Ex: aroma therapy, leisurely drive, bubble bath, listening to your favorite music).

Usually, families call for help when they feel they just can't take it anymore, when the stress becomes more than they can bear. **They don't ask for help because they think you can provide better care, and they may feel guilty about turning over the care of a loved one to others, even for a few hours per week.**

Give everyone a copy of the *Caregiver Fatigue Timeline*. Note that it doesn't take long for the stress of caring for another person to begin taking its toll, which makes the service you provide even more important.

Skills Building Exercise: Case studies *(Scenarios below are in the Participant's Workbook).* **Please make the point that these are worst case scenarios, and many families do not fall into any of these categories.**

If you have enough participants, have them break into three small groups. Assign each group one of the following scenarios. Ask each group to read their assigned case study and be prepared to answer the questions that follow that scenario when the whole class gets back together. (If the number of participants is very small, read and discuss one scenario together.) Note: There's almost always more than one right answer. Give everyone a chance to express their thoughts.

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.

If there's time, end the session with the following exercise:

Exercise: Clapping together

Form a circle with your group. Each person should stand with their feet shoulder width apart. The leader begins by turning at the waist toward the left or right. When the leader makes eye contact with the person next to them, both the leader and the person the leader is facing clap their hands at the same time.

Then the person who has just clapped with the leader should turn to the next person, and when they make eye contact, they should clap at the same time. Don't let the clap continue until each two people clap at the same time. At first, it may take several tries before they are in sync. The clap then travels around the circle.

Soon a rhythm will develop. The pace the clap travels around the circle should be as fast as a consistent rhythm will allow.

Point? We should all be "clapping" together to provide the best care possible for individuals with Alzheimer's disease or a related dementia.

Ten Minute Break

Session V

Making Activities Meaningful

Making Activities Meaningful

Beginning Exercise (use either of the following exercises to begin this session on activities)**:**

Exercise 1 – Describe yourself: Ask participants to describe who they are, in writing, in 1-2 sentences. They can use the back of an index card or sheet in the Participant Workbook. Give everyone about one minute to write the description. Then ask for a few volunteers to read what they have written. Did people describe *who they are* or *what they do*? Most of us define ourselves by what we do.

or

Exercise 2 – Favorite things:

- List five of your favorite things to do when you're not working (besides sleep).
- Look at your list, and cross out your favorite. (Get reactions from group about how they would feel if they could never participate in that activity again.)
- Now cross out a second activity that you really enjoy.
- Imagine not being able to do the activities that you love the most. How would your life change?

Points to make after either exercise:

- As people with Alzheimer's disease and related dementias progress through the stages of the disease, they become **less and less able**, on their own, **to initiate activities that most of us take for granted**, including activities of daily living, interactions with others and things we do just for fun.
- **Being is doing.** Activities are important to all of us. Helping someone continue to engage in an activity she enjoys is an important part of caregiving.
- Remember, **everyone who works with or interacts with a person who has memory loss is providing an activity**. The amount of fulfillment people get from doing the things that make up each day, with or without help, goes a long way in determining their overall satisfaction with life.

- **Daily activities**, including basic care and daily life events, **should reflect the choices an individual would have made had he/she been able to make those choices.**

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.** If it's something he enjoys and wants to do, it's an activity. If it is something that makes him feel needed or useful, it is definitely an activity.
- Getting a bath, washing her hair, shaving, having lunch, brushing his teeth, or eating a snack can all be activities. Doing the laundry, dusting the living room, cleaning out drawers or closets, sweeping or mopping the floor, baking a cake, or washing dishes can also be activities, as long as they are **part of the activity plan** and as long as it's **something that the worker and the care receiver do together.** The list of things you can do is endless.

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.

Guidelines for Choosing Activities

When choosing an activity, consider

The person with memory loss – Learn as much as you can about the person for whom you are providing care – medical, family and personal history, likes and dislikes, abilities, etc. To the extent possible, activities should reflect what that person would like to do.

The activity itself – Make sure it is **appropriate for an adult** and **failure-free.** Focus on enjoyment, **making the person feel valued and needed,** and allowing as much **independence** as possible. Adjust activities as necessary as the person's ability to function changes.

Your approach – Be positive, calm, realistic and flexible. Do not criticize or correct. Help get the activity started, if necessary, or help with difficult parts of the activity. Make it easy – without insulting the person. **Respond to feelings**, both verbal and non-verbal. Let the person know how much her help/participation/input is valued.

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 – and doing what the care receiver wants to do to the extent possible.

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. Take some time here to engage the students in some of the activities as time and supplies allow.

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, can be used to distract a person
- 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. (This would be a good place to stop and do a short exercise routine, with stretching, deep breathing, chair exercises, anything that gets everyone moving and gives them examples they can use with care receivers. There are two exercise routines on the CD, and you can search online for "chair exercises for seniors" or "exercise and dementia." You might also put on some music and invite participants to get up and dance, which combines the benefits of exercise and the enjoyment of music.

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!*"

Would You Rather…? Activity
Ask the class some of the *Would You Rather…* questions, and get their responses. (Ex: Would you rather eat a bug or be in a minor car accident?) Some choices will be easy; some funny; and others more difficult.

If there's time, have the group do the following exercise. If the group is small enough, they can all work together to develop one plan.

Skills Building Exercise: Developing an Activity Plan *(In Participants' Workbook)*

Before beginning the following activity**,** hand out *101 Things To Do With the Person Who Has Alzheimer's Disease* and refer participants to the Best Friends list of activities in this session.

Each table (or the whole group, if it's small) should choose one person with dementia and follow steps 1-6 together.

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.

Wrap-up and Evaluations