When You Forget That You Forgot:

Recognizing and Managing Alzheimer's Type Dementia, Part II

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INTRODUCTION AND OVERVIEW

>>Title Slide

At the end of Part I of this training program about dementia, we concluded that Alzheimer's Disease is incurable, but not untreated! There are many things caregivers can do to help the person be "the best that they can be." By careful assessment of the person’s abilities and the environment, caregivers can

- Preserve and enhance their remaining abilities;
- Avoid unnecessary stress and overstimulation;
- Treat illness or other complications (that make them worse); and
- Provide education and guidance for families and other caregivers.

>>Goals for today

In this second part of the program, we will review basic interventions to keep stress at a manageable level and help the person with dementia be as successful as possible. The goals for today are to:

- Review common sources of stress for people with dementia
- Review care principles based on the Progressively Lowered Stress Threshold (PLST) model of care, and
- Apply basic principles to care routines and approaches.

It is important to remember that the PLST model can be applied to a wide variety of behavioral and psychological symptoms in dementia. This is usually done in care planning meetings that think about the person with dementia and his/her unique characteristics and needs.

Today we will think about basic ways to change care routines and approaches based on the PLST model. In specific, we will look at ways to adjust our communication strategies and use principles of Validation Therapy to keep stress at a manageable level.

//Trainer: The slides about PLST Behavior and Sources of Stress are a review of content taught in Part I. This “refresher” provides important background to examine interventions. Take enough time to help the audience feel comfortable with the concepts. If much time has elapsed between the two programs, you may also want to re-use handouts related to behaviors and common causes of stress.
>>Behaviors in Dementia: New Culture

**Refer to handout: “The ‘New Culture’ of Dementia Care”**

A good place to start today is by thinking about changes that have occurred in dementia care over the last 10 to 15 years. Early in dementia care, lots of behaviors were labeled in pretty negative ways. Terms like disruptive, distressing, difficult, problematic, and aggressive were often used to describe behaviors in dementia. Although these labels are still in use, and are accurate in some ways (e.g., some behavior IS problematic!), there is a movement AWAY from using negative labels.

Unfortunately, labeling the BEHAVIOR as “disruptive” too often leads to thinking about the WHOLE PERSON as “the problem.” Person-centered care asks us to think about the individual’s strengths and abilities, not just losses and disabilities.

Today, we more often use labels like the ones on the slide:

- Behavioral and Psychological Symptoms of Dementia, or BPSD, which is the term used by the International Psychogeriatric Society;
- Need-Driven, Dementia-Compromised Behavior, or NDB, which is a term used by a group of researchers who believe many behaviors are the result of unmet needs; and
- PLST Behaviors, which is the term the PLST model uses to describe behavioral symptoms that are stress-related.

Thus, in this module, we will mostly refer to “problem” behaviors as “behavioral symptoms” or “behaviors in dementia.” Quotation marks are used to set off words that should be understood in the context (e.g., person has a “problem”) of the sentence.

DEMENTIA, PART I: REVIEW OF PLST MODEL

>>PLST Behaviors

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<th>This is what is on the slide:</th>
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<td>-- Increased anxiety</td>
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<td>-- Night awakening</td>
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<td>-- Catastrophic behaviors</td>
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<td>-- Sundowning syndrome</td>
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<td>-- Resistiveness</td>
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Although many behavioral and psychological symptoms are possible in dementia, the ones listed on this slide are considered “PLST behaviors.” By that, we mean that they are often related to stress that accumulates throughout the day. As the person experiences more stress, the greater the likelihood that behaviors like these will be observed.
As discussed in Part I of this program, "stress" can take many forms for those with Alzheimer’s disease and related disorders. Simple things that caregivers may take for granted may be very confusing and upsetting to the person with dementia. As indicated on the slide, being too tired (fatigue) and/or having too much, or the wrong type of stimulation, are common triggers to behavioral symptoms.

People with dementia often have chronic medical conditions and other physical illness that can cause discomfort – and that discomfort is observed in behavioral symptoms.

Changes in the person’s environment, daily routines, or caregivers can also be upsetting. As the person becomes more disabled, consistency in caregivers, personal care routines, and surroundings provides a sense of comfort and security.

It is important to remember that the “environment” isn’t just “outside” the person either – it includes the person’s “internal environment.” Thoughts and beliefs, physical sensations and psychological needs – like boredom or loneliness – also contribute to behavioral symptoms.
>>PLST: Sources of Stress → Demands, Negative feedback

This is what is on the slide:

-- Demands that exceed abilities
  -- Decisions that are too complex
  -- Tasks that are outside abilities
-- Negative and restrictive feedback
  -- “Don’t do that!”
  -- “Your parents are dead”
  -- “But this IS your house”
  -- “No, you’re not going to work”

As we discussed earlier, asking the person to make choices by using open-ended questions (e.g., What do you want to wear?), or pushing them to do things that are now too complicated given their level of ability, may also be stressful.

The PLST model also suggests that “negative and restrictive feedback” – repeated messages to the person with dementia that “YOU ARE WRONG” – can cause temporary sadness, fear, or anger that contribute to stress and later behavioral symptoms.

>>PLST: Care Planning Goal → Act like a prosthetic device

This is what is on the slide:

-- Goal: To act like a “prosthetic device” that supports the person to do what he/she is able to do
  -- Interventions serve like a memory “crutch” that fills in for lost abilities
  -- Supports person to be autonomous in spite of lost abilities
  -- Keeps stress at a manageable level throughout the day

The GOAL of the PLST model is for caregivers to act like a “prosthetic devise” to support the person to be as independent and functional as possible.

Just like an artificial limb can support a person with a leg amputation to walk, caregivers can act like a “crutch” for the person’s failed memory.

Interventions can be developed to cue the person, assist them as needed, and fill in what they don’t remember. By acting as a MEMORY CRUTCH, caregivers can help the person with dementia maintain their independence. This type of support and assistance helps to keep stress at a manageable level and reduces the risk of behavioral symptoms.

>>PLST: Care Planning Goal

As shown on this graph, the goal is to keep stress down, below the person’s stress threshold, throughout the day. By using rest periods in the mid-morning and afternoon, along with other interventions, caregivers can help reduce the amount of stress that the person with dementia experiences.
INTERVENTIONS

>>Interventions: Prevention is the best medicine

As we think about the person with dementia, and their progressive loss of abilities, we can see that "prevention is truly the best medicine" in terms of intervening in problem behaviors. Instead of waiting until you see a “problem” behavior, caregivers are wiser to adjust routines and change the environment to reduce the risk that behavioral symptoms occur in the first place! As we just saw in the graph, keeping stress below the person’s stress threshold is key.

Along with this, using “person-centered” approaches is very important.

>>Interventions: Person-Centered care

**Refer again to the Handout: “The ‘New Culture’ of Dementia Care”**

PERSON-CENTERED CARE means knowing THIS person and his/her life-long habits, routines, and preferences. It means thinking about long-standing personality traits, and life experiences. For example, a man who lived his life as a farmer will likely have different needs and preferences than one who taught physics at the university. It also means knowing the person’s strengths and abilities so care can be focused on what the individual can continue to DO – not the just losses that are part of the dementia.

Too often, caregivers are “caught up” in what the person CAN NOT DO – and forget about the long life they have lived, all the things they used to enjoy doing, and their retained abilities and interests. Knowing the person is essential to providing good quality care, as we will see later in the program.

>>Interventions: Multiple factor influence quality of care and life

As the PLST model suggests, lots of different things contribute to quality of care, and quality of life for those with dementia. As important, many factors INTERACT, making the situation better or worse! As noted on the slide, we need to think about all the ways the ENVIRONMENT can help the person feel calm, comfortable, and secure – or on the flip side, create stress and discomfort!

Facility and care routines are another important consideration – as we will talk about in just a few minutes. The WAY we talk to the person with dementia, the way we approach them and provide their daily cares, can make a tremendous amount of difference in their quality of life.

And we can never forget that the unique TYPE OF DEMENTIA – and the stage of dementia – makes a difference in what they can do for themselves, and how we can be helpful to them. Likewise, their unique PERSONHOOD – their strengths, abilities, and resources – will interact with the dementia-related losses and the environment. In short, lots of different things can contribute to stress and the development of behavioral symptoms!!!
**Care Planning: PLST Principles – Underlying Assumptions**

**Refer to the handout: “Progressively Lowered Stress Threshold (PLST) Principles”**

It is important to remember that the PLST model is based on some basic, underlying beliefs. So before we review WHAT to do, let’s think a bit about WHY we do it! As noted on the slide, there are four basic beliefs, or “assumptions” about people and dementia:

- **All people need some kind of control over themselves and their environment.** Some people might call this having a sense of “personal power” – or the ability to influence what happens to us on a day-to-day basis. The point in dementia care is that we too often TAKE AWAY control – sometimes as an issue of safety (e.g., like driving or going out alone), but sometimes we do it for our own convenience. So one basic idea is to help those with dementia maintain as sense of control over their life.

- **All behavior has meaning.** Just like we “listen” to small children who are not able to talk yet, to “decipher” the meaning of their behavior (e.g., crying can mean hunger, being wet, wanting to be held), we need to “listen” behaviors in dementia to figure out what they mean.

- **Behavioral symptoms are a signal of discomfort.** PLST behaviors are a “red light” that the person with dementia is not comfortable – and needs our help to become comfortable again.

- **Persons with dementia live in a 24-hour continuum.** Although lots of care settings operate on an 8-hour shift basis, the person with dementia lives in a 24-hour continuum. Remember, STRESS ACCUMULATES – so what happens on days will influence what happens on evenings and on nights and around and around! We have to think about, and plan for, the “big picture”!!

**Care Planning: PLST Principles: Six basic ways to improve care**

The PLST model includes six basic ways that we can promote high quality care. The first three are listed on this slide.

1. Maximize safe function by supporting losses in a prosthetic manner.
2. Provide unconditional positive regard
3. Use anxiety and avoidance to gauge activity

As you can see, these principles are really closely related to the underlying assumptions about people with dementia! In a minute, we will look at some ways that we can change what we DO to support these principles.

>>Care Planning: PLST Principles, continued

4. “Listen” to the person with dementia (what does the behavior “tell you”?)

5. Modify the environment to support losses and enhance safety

6. Encourage caregivers to participate in ongoing education, support, self-care, and problem-solving

As before, these principles are very understandable, particularly when we think about losses associated with dementia, and the person’s reduced ability to manage stress. Those providing care need to “fill in the gaps” and help the person function. To do that, caregivers often need to

- Get needed education and training;
- Take “time out” to do something nice for themselves and being with supportive others (e.g., respite for family caregivers, time off for formal caregivers, support groups for both); and
- Avoid trying to solve care challenges alone! Team work really DOES work!

PLST CARE PLANNING

>>Care Planning: PLST Principles – Many ways principles are applied in practice

**Refer to handout: Interventions: Management and Care Planning**

Please remember that the program today is the proverbial “tip of the iceberg”!! There are many, many ways that the PLST principles can be applied in day-to-day practice. The most effective way to use the model is to apply it to the care of a person with dementia in a care planning meeting. That way, the basic principles and care strategies can be individualized to meet the current needs of the person with dementia.

The rest of this program reviews some of the most basis points about HOW to adjust care routines and practices based on the model.

>>PLST Care Planning: Reduce environmental stress

Remember – the idea is to keep stress at a minimum for the person with dementia. Some of the things that the ordinary person is able to filter out, or manage, is UN-manageable to those with dementia. An important first step is to look seriously at the environment – whether that is the person’s home, apartment, assisted living residence or nursing home. What is it like? What might present problems for the person with dementia? How can we modify it to make it less stressful and more understandable?
As noted on the slide, the goal of REDUCING ENVIRONMENTAL STRESS often includes adjusting a number of things that can increase, or contribute to stress among people with dementia:

- Eliminate caffeine – which promotes restlessness, agitation, and sleeplessness
- Misleading stimuli – TV, radio, PA systems are not understood and can cause fear
- Unending spaces – long corridors that seem to go on and on may cause fear
- Unneeded noise – radio, TV, people talking outside the room may all contribute to stress
- Extra people – avoiding large groups that may increase noise and confusion and contribute to stress may help avoid behavioral symptoms
- Large rooms – any room that by design is for a large group (dining, day, activity rooms) may be over-stimulating to the person

//Trainer: Ask participants to reflect on the presence of these environmental stressors in their LTC setting.

>>PLST Care -- Compensate for lost abilities by adjusting APPROACHES

//Trainer: Examples and illustrations are provided for each of these in the handout. Take time to illustrate and discuss how these changes may be used in your care setting.

The second step is to look at the INDIVIDUAL, and think about how we can act as a "prosthetic device" for that person. What can we do to counteract their loss of thinking and planning abilities? One important change is to modify OUR APPROACH with the person, remembering how stressful "negative feedback" can be.

- Calm, consistent approach and routine
- Do not try to reason with client
- Do not ask them to "try harder"
- Do not try to teach them new routines
- Do not encourage them to try to recover lost skills

>>PLST Care Planning: Compensate for lost abilities by adjusting ROUTINES

We can also compensate for the person’s lost abilities by modifying OUR ROUTINE. Seemingly “simple” changes in how we provide day-to-day care can make a HUGE difference in their ability to perform activities of daily living. Remember – one of the underlying beliefs is that “all people needs some degree of control” – and we can help them feel “in control” by NOT doing...
Limit choices to those the resident can make

Monitor changes in the environment

Eliminate changes in pace

Plug Care Planning: Allow for LOWERED STRESS threshold

In addition to reducing stress in the environment and compensating for lost abilities, caregivers also need to think about interventions that allow for the person’s lowered stress threshold in general.

Remember that FATIGUE is a big contributing factor to stress. Even a person who has always been "on the go" will need assistance to modulate activity with rest. And although lots of people believe “variety is the spice of life”, ROUTINES – not variety – keep the person with dementia healthy and well!!

Plan rest periods in morning, afternoon

Maximize routine: eat, rise, rest at same time

Alternate high and low stimulus activity

Reduce stimuli (quiet environment) when reactions occur

Keep records and look for triggers (internal/external)

PLST Care Planning: Provide unconditional positive regard

Perhaps one of the MOST IMPORTANT things that caregivers and others around the person can do is avoid treating the person with dementia resident like a child. Remember, we are working with an ADULT who is still aware of how things are said, and experiences feelings and emotional reactions just like everyone else. They deserve respect and consideration just like everyone else.

Use one-to-one communication

Use touch to reassure

Eliminate "you are wrong" messages from environment

Do not confront; DISTRACT!

Simply communication
- Use Validation vs. Reality Orientation
- Don’t confront hallucinations or delusions

One of the most important ways that we can show our respect for a person is through the way that we talk to them. We may slip into thinking, "Oh, what difference does it make? They don’t know what I’m saying anyway.” But that kind of thinking is NOT helpful to THEM or to US.

>>Positive Regard: Communication

**Refer to handout: Interventions: Communication**

// Trainer: There is an additional page of “General Guidelines” on page 2 of the handout if you would like to include those ideas in the lecture and discussion.

As the last slide suggested, communication strategies are an IMPORTANT part of day-to-day care. The way that we communicate with the person with dementia MAY show RESPECT and helps to promote

- Cooperation – because they can follow what we are saying, or wanting;
- Comfort – because we are talking at a level that they understand; and
- Dignity – because we are not challenging them to use lost abilities, and reminding them of what they cannot do now!

In short, communication is a very, very important part of care provided to the person with dementia. These strategies can either INCREASE STRESS – OR can help the person BE SUCCESSFUL in daily routines and activities. The guidelines that we're going to review now were developed many years ago by Mari Anne Bartol and Michael Storrie, and were published in the Journal of Gerontological Nursing. Their article is so widely respected that the Alzheimer's Association put it on their resource list, and the approaches they recommended are still widely used today.

>>Communication Strategies: Simplify the MESSAGE

First, it is important to remember that aging processes cause changes that affect ALL older adults, including those with dementia. So first, think about things like lighting, ability to see, hearing, and background noise. Then we want to simplify the message. For example,

- Use short understandable words – there is no need for long or complicated words.
- Use simple sentences – that that means one noun and one verb. Avoid sentences that have several pieces (compound) or meanings (complex).
- Take pronouns out of your message and use the noun instead. Leave out "there, that, them, those, they, him, her, and it.” Instead, use the noun. Say, "Sit in the chair" instead of "Sit here."

>>Communication Strategies: Simplify the MESSAGE, continued

- Begin each conversation (particularly at night) by identifying yourself and calling the person by name.
  - Tell the person who you are
  - Call the person by name
  - Cue the person by providing needed information

The NEXT step is to simplify your STYLE of talking! Caregivers need to modify the "way we say" what we say – our style of speech. This includes:

- Speaking slowly.
- Saying individual words clearly.
- Be careful to not use slang or to slur words. Think about the words the person with dementia commonly uses, and USE THOSE WORDS OR LABELS.

>>Communication Strategies: Simplify your STYLE, continued

- If you increase your speech volume, lower the tone of your voice. Raise the volume of your voice only for deafness, not because you do not get a response you understand!
- If you ask a question wait for a response. Give them time to think the question through and come up with their answer. Be patient! Don't assume the person paused because they didn't understand.
- Ask only one question at a time. Asking the person to think about more than one thing at a time can cause MORE confusion – and increases the risk that you get ANY response.

>>Communication Strategies: Simplify your STYLE, continued

- If you repeat a question, repeat it EXACTLY! Unlike other situations where we might assume that we need to "re-phase" if we don't get an answer, the person with dementia is best helped by asking the same simple question again.
- Use self-included humor whenever possible. Don't be afraid to laugh at yourself or the situation, as long as you are not laughing at the person!

>>Communication Strategies: Non-verbal messages

Non-verbal messages only become MORE important when we work with those who have dementia. THINK carefully about your nonverbal MESSAGE! What are you “communicating” by the look on your face? the tone of your voice? the gestures that you are using?

To promote the most effective communication, consider the following principles:

- Convince yourself that your nonverbal style can be felt all the way across the room and by several people, not just the patient or staff person you are addressing.

- Use gestures to help them understand the meaning of your message. Try to make sure that every verbal communication is delivered by proper non-verbal gestures. Point, demonstrate, and use your hands and body to help them get the meaning!

**Communication Strategies: Non-verbal, continued**

- Stand right in front of the person. Make sure that they see you and that you have their attention.

- Maintain eye contact. Get them to look at you. That way they see your facial expression, your gestures, and you have a better chance of "being heard."

- Move slowly. Remember that you risk setting off a catastrophic reaction. Don't threaten them with surprises.

- If the person starts or continues to walk while you are talking to him, do not try to stop him as your first move. Instead keep moving along in front of him and persevere.

- Use overemphasis and exaggerated facial expressions to emphasize your point, particularly if their vision or hearing is impaired.

**Communication Strategies: Avoid “you are wrong” messages**

The last communication strategy is to avoid “you are wrong” messages. As we talked about earlier, caregivers often are tempted to “correct” the person with dementia. People with dementia say things that are not accurate – they want to go to work, visit a parent that is dead, go home, leave, take something that isn’t theirs – the list goes on and on. The point is that is THEIR REALITY. Because of the dementia, those thoughts are quite real to them. When we “correct them” – by saying the things listed on the slide, we add to their stress. They react to our reality orientation by becoming angry, hurt, and frustrated. As important, they don’t REMEMBER what we said, and are likely to ask again later, and with every “correction” we add to their stress level.

**Positive Regard: Validation**

Another important way that we can show unconditional positive regard to the person with dementia is by using “Validation” instead of “Reality Orientation.” Now, most of us were taught that when a person is DIS-oriented, we need to help them become RE-oriented. And being “oriented” means understanding our “shared” reality of time, place, people, and things around us.

In dementia, permanent memory loss keeps people from remembering what they are told. Try as we might to “reorient” the confused person, it often doesn’t work. A more helpful approach is Validation Therapy. Since we often use BOTH approaches in daily care, let’s take a minute to look at the differences between the two.
>>Reality Orientation: Basic Beliefs

Reality orientation (RO) stresses the importance of bringing the disoriented person back to the "here and now" by constantly emphasizing the four spheres of orientation (time, place, person, thing). RO is based on the belief that disoriented persons are able to return to the present, if given enough information to do so. Consequently, the method encourages us to CORRECT people who are disoriented or confused, and to provide accurate information that will help them stay in "the present."

>>Reality Orientation: Advantages

Reality orientation is useful with persons who are, in fact, temporarily confused but not permanently impaired. A person who is acutely confused because they have an infection (e.g., are delirious) or because they recently moved to the nursing home should be reoriented. That person needs to be provided accurate information to be reminded of the correct time, place, person, and things that are happening.

Reality orientation can also be used effectively with people who have chronic confusion, like dementia. For example, by talking about the date, date, or time of year in the course of providing care, we are "orienting" the person. The point is to not "test" them by saying things like “Do you know who I am?” or “What day is today?”

>>Reality Orientation: Disadvantages

For the most part, reality orientation is not useful with persons who have memory loss and are intellectually impaired, like those with dementia. The progressive loss of memory caused by dementia means that the person lacks the ability to retain the information. Constant orientation, or contradiction of their stated beliefs (even when false) only functions as "negative feedback" – the message that "you are wrong."

As we just discussed, these YOU ARE WRONG messages typically irritate, agitate, and embarrasses the person with dementia. At some level they "know" and their self esteem is damaged by constant reminders that they are "wrong." The other issue is that constant questioning feels like being “tested” – which makes lots of people uncomfortable, particularly when they don’t know the answer!

>>Validation Therapy

A better approach in the middle and later stages of dementia is to provide care that is consistent with Validation Therapy (VT). Validation stresses the importance of "going with the person" to their reality to better understand what they are experiencing. VT suggests that some elderly may withdraw from the "here and now" because it is too painful and distressing. They return to their past, which is more pleasant and comforting, to avoid the present. VT recommends listening carefully to the words, phrases, and statements that the person uses to understand what they mean. Then we may be able to "bring the person to the present" by gently prompting their memories about both the past and the present.
We will never know for certain if people with dementia “withdraw” because the present is too painful. What we can see is that NOT confronting people with OUR reality is a kinder, more compassionate and person-centered approach. There is little sense in “arguing” with a person who cannot remember. We show respect by “going to their reality” – even if it is just long enough to distract them to another idea or activity!

>>Validation Therapy: Advantages

Validation of the person’s reality avoids sending negative feedback to the person with dementia who may believe that they are "going to work" or that they visited with "mother or father." Instead of contradicting the person, we can "go with them" and talk about what they are remembering at that moment. Through the reminiscence we may be able to help them feel more positive, instead of sending the message "you are wrong" that is likely to bring out sad or bad feelings.

>>Validation Therapy: Disadvantages

The person with dementia may respond to validation techniques at the time that they are being used, but will not retain the abilities that they may momentarily show. For example, validation techniques may help the person realize that their daughter is their daughter (and not their mother) during the time she visits. However, that realization will be lost after the visit and the process will need to be repeated on the next visit. In addition, validation techniques may be inconsistent in reassuring the person, which may be frustrating.

Of perhaps most importance, is overcoming the barriers to using Validation approaches. Lots of caregivers, including family members, feel like they are LYING to the person. And of course, lying is wrong. On the other hand, “hitting” the person – psychologically that is – with information that is hurtful to them is also wrong. We believe that validation approaches, combined with distraction, redirection, and reminiscence, is a kinder approach that allows the person to think comforting thoughts. We don’t have to AGREE with the person – we simply avoid OPEN CONTRIDICTION of their beliefs.

Perhaps the best way to understand Validation is to review a few examples.

>>Validation Therapy: Don’t confront the person’s misbelieve

//Trainer: If possible, use “true stories” from your own experience, or from the care setting in which caregivers work, to personalize the concepts described below.

As we have discussed, there is little value in confronting and “correcting” the person’s misbeliefs. Instead of saying “No, you live here now” or some other “reality-based” statement, think about what the person is thinking. They want to go home – and going home is often a need for comfort, reassurance, or feeling safe and cared about. So trying distracting them briefly with an explanation of why going home isn’t possible right now – like being too cold, too late, having no car right now – and inviting them to stay with you for time. Then redirect to an activity that might help them feel the comfort that they seek in “going home” (e.g., companionship, food, activity).
**True Story:** A caregiver told the story of a man who wanted to go home. She told him there was no car to take him home and invited him to stay with her. He then asked “How did you get here then?!” She was taken back, but responded that her husband brought her to work. She invited him to come to supper, and later convinced him to “stay over night in the nice room that was just for him.”

**>>Validation Therapy: Avoid “you are wrong” messages**

As before, giving the person the “correct” information is another way of saying “you are wrong.” Think carefully about what the message may mean to the person – he wants to visit his father. What does that represent? He is likely missing his father and thinking about him. Instead of telling the man his father is dead, try to get the person to talk with you about his father.

**True Story:** George, a resident in a nursing home, often wanted to go visit his father. Each time the staff replied that his father was dead. George appeared shocked by the news and said “No one told me. I didn’t even go to the funeral. I am a bad son!” Staff were so convinced that George was “joking” with them that they asked family member to bring a copy of the obituary. George responded the same way, crying and feeling deeply sad. Staff stopped confronting George, and instead talked with him about his father. They learned that George loved his father deeply and missed him very much. By looking at old pictures, and letting George reminisce about the “good times” they had over the years, he often remembered that his father was now dead.

**>>Validation Therapy: Listen carefully to “nonsense”**

As the person with dementia loses their ability to use language, they may substitute words or phrases that don’t seem to make any sense. Too often, caregivers just think of these messages at “nonsense” that has no meaning. However, if we listen carefully to the words and think about the situation, time of day, and other things the person may be doing, we may be able to figure out what the meaning is. In many situations, family members may be able to help “decipher” seemingly odd behavior that related to the person’s past history and experiences.

**True Story:** Harvey regularly called out “Whoa! Whoa! Ho, ho, ho, ho, ho, Who up there!!! Up, up, up, up, up, up there!” while waving his hands while sitting in his recliner. Telling him to stop or be quiet only made him angry, leading to cursing and name-calling. By talking with family, staff learned that in his youth, Harvey rode a horse to round up the cattle in the timber. His father was very harsh with him if he did not get his chores done – and to family, the “Whoa, up there” sounded like he was calling to his brother for help. When Harvey began calling out, staff made eye contact with him the said, “The cattle are in. The gate is closed. It’s done.” Harvey looked puzzled but stopped briefly. When he started again, the staff repeated their statement, adding, “Come with me. Let’s go check.” They reassured him again that the cattle were safe and the work was done for the day. Praise for his hard work and care of the cattle often reduced his worried look. The combination of reassurance and walking regularly helped Harvey become calm enough that he could be distracted to another activity, like having a snack.

**>>Validation Approaches: Misbelief vs. delusions and hallucinations**

**Refer to handout: Interventions: Managing Delusions & Hallucinations**

//Trainer: Additional information and ideas about responding to delusions and hallucinations is provided in the handout. Review as much as needed to assure caregivers can distinguish between “harmless” and “troubling” false beliefs and sensations.

Distraction and redirection are often useful with “harmless” false beliefs – things like wanting to go home. These MIS-beliefs are based in the person’ past experiences and regularly represent a sense of longing – of missing something or someone that has been important to them.

Delusions, which are also false beliefs, are generally more bizarre and troubling – both to the person and to those around him or her. For example, thinking that someone is spying on them, stealing from them, poisoning their food, or physically abusing them can ALL be very upsetting. In some cases, there may be a basis for the belief. For example, they see their own reflection in the window at night and think someone is outside spying on them. In other cases, the belief is not founded, and may interfere with wellbeing – like refusing to eat for fear of being poisoned. Hallucinations, which are false sensory experiences, are also possible. The person “sees” their dead husband or wife. They “hear” a voice that we don’t. The point is to consider how disturbing the experience is TO THE PERSON.

Although we don’t want to “correct” the person, providing accurate information may be useful. For example, “I don’t see anyone there, but come with me. Let’s have someone check.” Monitoring the person’s response to validation approaches AND their level of distress is critically important to know what is needed.

>>Validation Approaches: Don’t

In summary, we don’t often use Validation “Therapy” as often as we use Validation principles and approaches. We try to AVOID reasoning, arguing, and confronting the person. There is little point in reminding them they forgot (e.g., I just told you that!) or asking questions that rely on recent memory (Don’t you remember what I said?). Most important, if the person is frustrated or unhappy, we need to remember to not take what they say too personally!

>>Validation Approaches: Do

<table>
<thead>
<tr>
<th>This is what is on the slide:</th>
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<tbody>
<tr>
<td>-- Allow for your message to “sink” in</td>
</tr>
<tr>
<td>-- Slow down. Take your time – even when you are in a hurry!</td>
</tr>
<tr>
<td>-- Take “but” out of your vocabulary</td>
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If we combine basic communication principles with Validation approaches, we will likely want to the things listed on the slide. Slow down, let the message sink in. Remember, taking time now may help keep stress at a manageable level and reduce the risk of PLST behaviors later on.
>> Validation Approaches: Do

<table>
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<th>This is what is on the slide:</th>
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<tr>
<td>-- Distract them to a different subject, activity</td>
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<tr>
<td>-- Accept the blame for misunderstandings (<em>even when you know better!</em>):</td>
</tr>
<tr>
<td>-- “I’m sorry. I didn’t mean to frighten you.”</td>
</tr>
<tr>
<td>-- “I’m sorry if that hurt.”</td>
</tr>
<tr>
<td>-- Leave the room to avoid confrontations</td>
</tr>
<tr>
<td>-- “I’m going to the kitchen now. I’ll be back.”</td>
</tr>
<tr>
<td>-- “Let’s stop now. We’ll do this later.”</td>
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Although distraction and redirection are often helpful, sometimes these strategies don’t work. Even though we told the person what we were going to do, they still get upset. They may resist the care we are trying to provide. In those cases, it is generally best to apologize for the misunderstanding – even if you think it is an “over reaction.” And sometimes, just leaving and starting over again later is the best thing to do.

>> Validation Approaches: Do

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<tr>
<td>-- Respond to feelings, not words</td>
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<tr>
<td>-- Be patient, cheerful, reassuring</td>
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<tr>
<td>-- Go with the flow</td>
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Remember, what you say is probably less important than HOW you say it! Yes, using simple and easy-to-understand language helps, but making the person feel safe and cared about is probably more important! As before, following the person’s “lead” and thinking about his/her AGENDA regularly produces more positive outcomes.

>> Validation Approaches” Do

<table>
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<tr>
<th>This is what is on the slide:</th>
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<tbody>
<tr>
<td>-- Listen carefully to type and extent of false beliefs</td>
</tr>
<tr>
<td>-- Monitor level of distress experienced by the person</td>
</tr>
<tr>
<td>-- Persistent, severe, and troubling beliefs may reduce comfort and functions</td>
</tr>
<tr>
<td>-- Short-term, low-dose medication may be needed</td>
</tr>
<tr>
<td>-- Try all other approaches first!</td>
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</table>

As before, misbeliefs and “simple” false beliefs may become quite distressing to the person with dementia. The false beliefs or false sensory experiences are persistent and severe, they may interfere with both the person’ comfort and ability to function. In those cases, using a low-dose of medication may be needed to help the person feel better. However, first we need to check out ALL the possible things that might be contributing to the false belief (like hearing water dripping and thinking it is a voice!), changing things to reduce misinterpretations and illusions, and using distraction, redirection and reassurance to help the person become calm and comfortable again. Only when those things fail, should we even THINK about medication!
>>PLST Care Planning: Problem-solving requires good documentation

It's important to document what happens in very specific terms. Generalizations are not helpful in better understanding what causes or precipitates behavior, whether catastrophic or confused. Describe the behavior!! Is the person

-- demanding? In what way?

-- disoriented? In what sphere? time, place, person, thing?

-- delusional? What about? What did she say? Do?

Specific description is needed to know what might be causing the problems.

What was happening in the environment before the catastrophic response? Who was the patient interacting with? At what time of day? In order to find develop interventions to reduce the risk that behavioral symptoms occur, we MUST know what the “triggers” are!

>>PLST Care Planning: Evaluate care

And finally there are a lot of things that can be monitored to evaluate whether these interventions are really being helpful to the person.

- Sleep patterns: If stress is kept at a manageable level through out the day, they should be less restless during the night

- Food intake/Weight: By simplifying the environment (like reducing noise and confusion during mealtimes and offering food that is “understandable” to the person), nutrition and hydration can be maintained

- Incidents/Outbursts: The number of times the person experiences PLST behaviors should be reduced if caregivers are effectively managing daily routines to reduce stress

- Medication use: Less medication should be needed if we substitute nursing care strategies and meaningful activities that calm, soothe, reassure, and redirect the person away from distressing thoughts and behaviors

- Family's feedback: The calmer, more functional and engaged the person with dementia is, the greater the likelihood that family members will be satisfied with their loved one’s care

SUMMARY

>>Alzheimer's Disease: Incurable but not untreatable

Just as we said at the beginning of the program, Alzheimer's Disease and related dementias are incurable, but this doesn't mean that they aren’t treatable! There are many things that caregivers
can do to help the person be "the best that they can be!" By careful assessment of their abilities and the environment, we can

-- preserve and enhance their remaining abilities;
-- avoid unnecessary stress and overstimulation;
-- treat illness or other complications (that make them worse); and
-- provide education and guidance for families and other caregivers.