

Changing Resistance to Care to Participation in Care



Caring for Someone with Dementia: How You Help Makes a Difference

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How Can We Help With Resistive Behaviors?

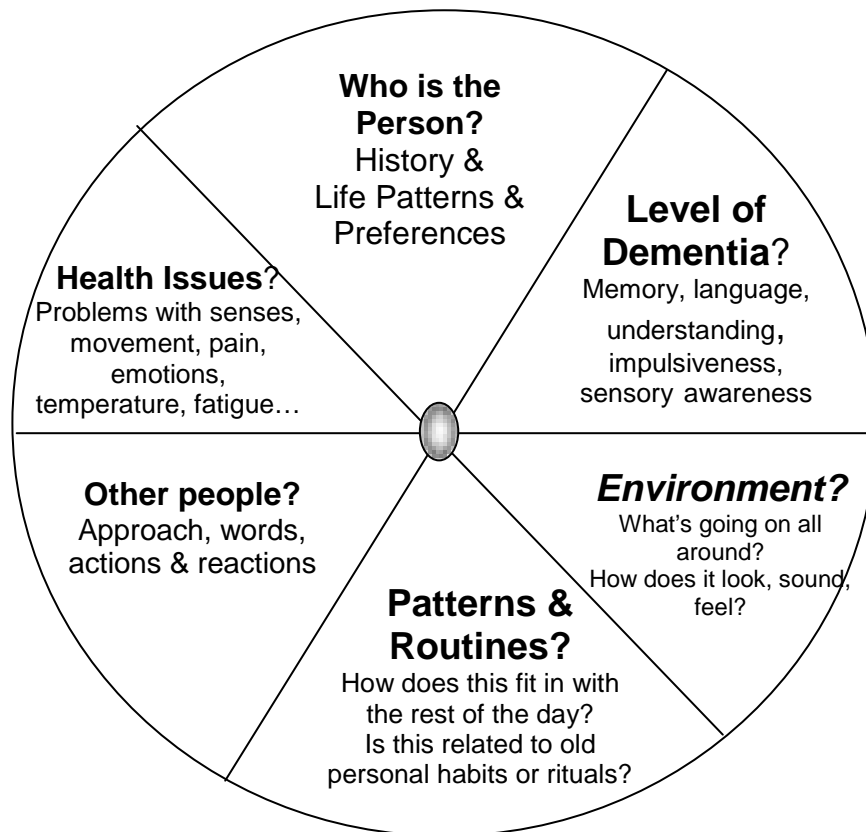
FIRST – Describe the Behavior

Use *OBJECTIVE* words

What happens? Where does it happen? Who is involved? When does it happen?
What else has been going on during the day?

THEN... Figure out what you know and what you don't know!

Take the time to fill in ALL the pieces of the puzzle!



NOW --- BRAINSTORM –

Given all the pieces of the puzzle... What do you think is going on?
How would you explain the behavior of this person?

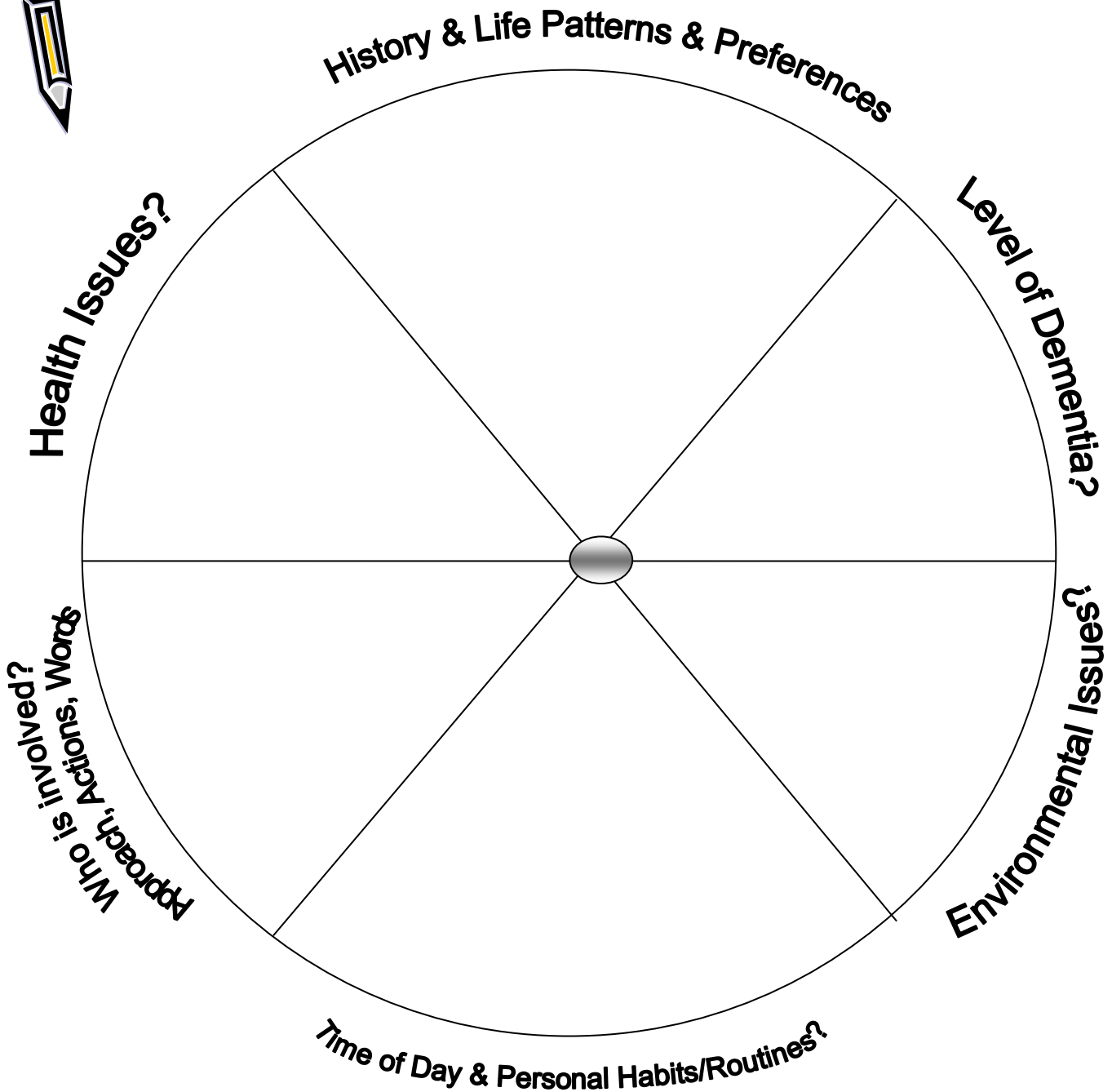
THEN --- COME UP WITH AN ACTION PLAN!

What will you try?
How do you think it might help?
How will you know if it works?
Who will be doing what?

First – Describe the Behavior – Be Objective

What happens?
Where does it happen?
When does it happen?
Who is involved?
What is said? Done?
How does it start? Stop?

Then - Review what you know and don't know. Fill in all the parts of the puzzle.



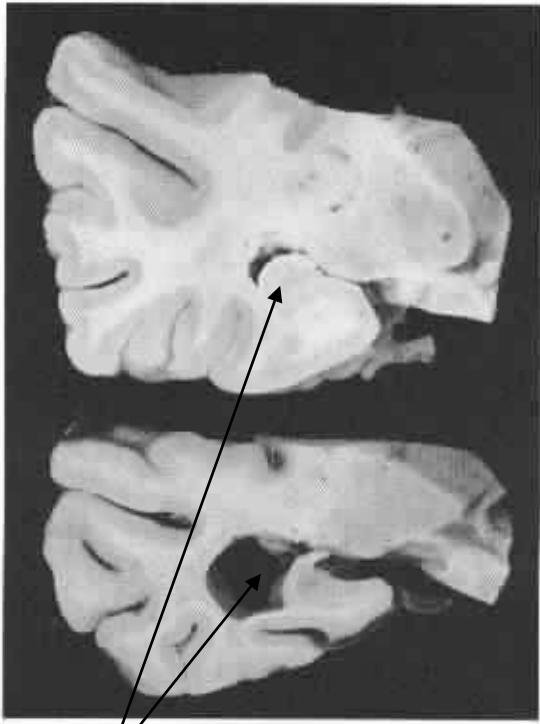
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Given all the pieces of the puzzle... What do you think is going on?
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THEN --- COME UP WITH AN ACTION PLAN!

What will you try?
How do you think it might help?
How will you know if it works?

Normal



Alzheimer

The ability to remember information...

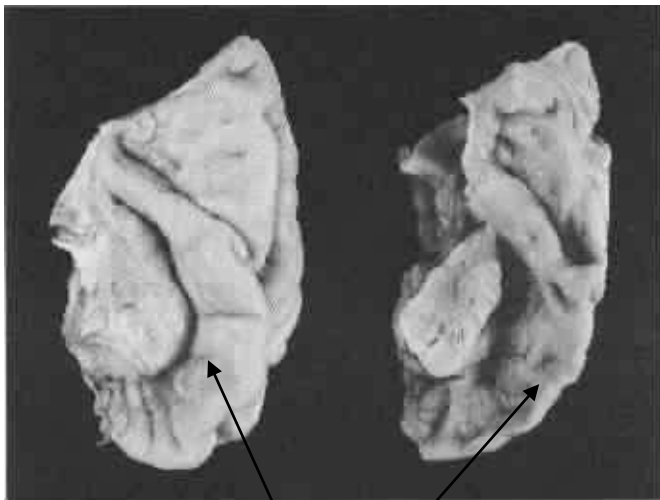
Normal



Alzheimer

The ability to use words and language...

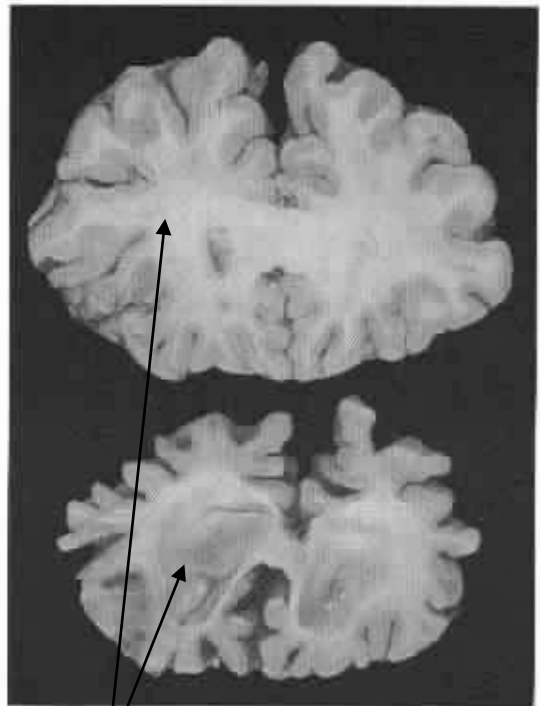
Normal



Normal

Alzheimer

The ability to understand what is being said...



Alzheimer

The ability to control your impulses, temper, & moods...

REALIZE ...

It Takes TWO to Tango ... or tangle...

- By managing your own behavior, actions, words & reactions you can change the outcome of an interaction.
- Being 'right' doesn't necessarily translate into a good outcome for both of you
- Deciding to change your approach and behavior WILL REQUIRE you to stay alert and make choices... it is WORK
- It's the relationship that is MOST critical NOT the outcome of one encounter

As part of the disease people with dementia 'tend to' develop typical patterns of speech, behavior, and routines. These people will also have skills and abilities that are lost while others are retained or preserved.

Typically Lost – can't use

Memory skills

- immediate recall
- short term memory
- clarity of time and place
- depth of categorical information
- relationships & specifics

Understanding skills

- interpretation of abstract meaning
- early - misses ¼ words
- later – misses ½ words
- subtle emotions, 'unspoken' agreements
- at the end – most words

Language use skills

- specific word finding
- descriptive abilities
- reading for content
- content of speech
- spoken communication
- words
- meaningful 'yes' and 'no'
- socially acceptable expressions of emotion
- verbal communication of needs and desires

Emotional & Impulse control skills

- ability to 'demand' respect
- ability to limit or control emotions
- ability to control impulsive speech
- ability to control impulsive actions
- don't act out when 'pushed'
- ability to keep private thoughts and actions in private places

Motor Skills & Sensory Processing

- at first very little as far as skills go
- later – initiation or getting started
- later – parts of tasks get left out/skipped
- mis-interprets sensory information
- organized scanning is lost
- visual field is restricted
- may become hypersensitive OR hyposensitive to touch, sound, light...

Preserved – can or may use

Memory skills

- long ago memories
- emotional memories
- confabulation
- procedural memories
- awareness of familiar versus unfamiliar

Understanding skills

- 'gets' the concrete meaning
- picks out familiar or meaningful words
- covers well
- facial expressions that are consistent with the message being sent

Language use skills

- desire to communicate
- ability to use hands or actions to describe
- reading aloud
- rhythm of speech
- para-verbal communication (how you say it)
- music and song
- automatic speech
- swearing, sex words, 'socially unacceptable' words
- non-verbal communication of needs and desires

Emotional & Impulse control skills

- desire to be respected
- ability to feel emotions and have needs
- say what is on your mind – with errors
- do what you want to do
- sometimes, feel badly after its done
- sometimes, behaving differently in 'public' if cues are strong

Motor Skills & Sensory Processing

- the movement patterns for pieces of tasks
- gross motor movements last longer than fine motor
- can often do the mechanics – BUT not safely or well
- looks for stuff – seeks out things
- mouth (lips, tongue), fingers and palms, soles of feet, & genitalia or 'private body parts'
- recognize faces, voices – familiar from not familiar

Progression of the Disease – Levels of Cognitive Loss

Diamond - Level 5 – Early Loss – Running on Routine – Repeating Stories

Some word problems and loss of reasoning skill
Easily frustrated by changes in plans or routines
Seeks reassurance but resents take over
Still does well with personal care and activities
Tends to under- or over-estimate skills
Seeks out authority figures when upset or frustrated
Points out others' errors, but doesn't notice own behavior
May have awareness – “Just not right” – might blame others or self
Can't remember 'new' rules, locations, plans, discussions, facts – does back to the familiar

Emerald - Level 4 – Moderate Loss - Just Get It Done! – Wanting a Purpose and a Mission

Gets tasks done, but quality is getting to be a problem
Leaves out steps or makes errors and WON'T/CAN'T go back and fix it
Can help with lots of things – needs some guidance as they go
Likes models and samples – uses others' actions to figure out what to do
Asks “what /where/when” LOTS
Can do personal care tasks with supervision & prompts – often refuses “help”
Still very social BUT content is limited and confusing at times
May try to 'elope' /leave to get to a 'older' familiar time or situation OR get away from 'fighting'
Can't remember what happened AND can mis-remember it – goes back in time, at times

Amber - Level 3 – Middle Loss - See It – Touch It – Take It – Taste It – Hunting & Gathering

Touches and handles almost anything that is visible
Does not recognize other's ownership – takes things, invades space, gets 'too close'
Can still walk around and go places – 'gets into things'
Language is poor and comprehension very limited - does take turns
Responds to tone of voice, body language and facial expression
Loses the ability to use tools and utensils during this level
Does things because they feel good, look good, taste good – refuses if they don't
Stops doing when it isn't interesting anymore
Can often imitate you some – But not always aware of you as a person

Ruby - Level 2 – Severe Loss – Gross Automatic Action – Constant GO or Down & Out

Paces, walks, rocks, swings, hums, claps, pats, rubs....
Frequently ignores people and small objects
Doesn't stay down long in any one place
Often not interested in/aware of food – significant weight loss expected at this level
Can grossly imitate big movements and actions
Generally enjoys rhythm and motion – music and dance
Doesn't use individual fingers or tools (more eating with hands)
Either moves toward people and activity (feels like a shadow) or leaves busy, noisy places (ghost)
Chewing and swallowing problems are common – soft, ground, or puree food may be needed
May not talk much at all, understands demonstration better than gestures or words

Pearl - Level 1 – Profound Loss - Stuck in Glue – Immobile & Reflexive

Generally bed or chair bound – can't move much on own
Often contracted with 'high tone' muscles - primitive reflexes reappear
Poor swallowing and eating
Still aware of movement and touch
Often sensitive to voice and noise - startles easily to sounds, touch, movement...
Difficulty with temperature regulation
Limited responsiveness at times
Moves face and lips a lot, may babble or repeatedly moan or yell
Give care in slow, rhythmic movements and use the flats of fingers and open palms
Keep your voice deep, slow, rhythmic and easy as you talk and give care
Move into the central field of vision to communicate
Use rotation and slow motion, not 'prying' or 'pulling' to get to hard to reach areas for care

A Positive Approach

- **Come from the FRONT** – let them know you are coming
- **Go SLOW** – reaction times slow as we age – it takes longer for info to get in
- **Get to the SIDE** – be supportive NOT confrontational
- **Get LOW** – don't use your height to intimidate
- **Offer HAND** – let them start the interaction
- **Call NAME** – the name that person PREFERS!
- **THEN wait.....**

- **Start Message**
 - **Give basic information**
“It's time to...”
 - **Give simple choices**
this or that (orange juice or milk) (eat or go to the bathroom first)
 - **Give single step directions**
break down the task (to go to eat.... lean forward..., pull your feet in...)
 - **Ask the person to HELP you**
it feels better to give than to receive!
 - **Ask the person if they will at least TRY??????**
sometimes you'll try even if you don't think you can!
 - **DON'T Ask** “Are you ready?...???” “or “Do you WANT to...?”
 - **DON'T have verbal diarrhea**

- **WAIT for a response (silently count to 10)**
IF No response ... ask again

IF Responding
 - **Give positive STROKES - Feedback**
 - “Good job!”
 - “Yes!”
 - “That's it”
 - smile, nod
 - hug
 - stroke or rub

REMEMBER – You HAVE THE POWER!

Keep it Calm!

Keep it Adult!

Keep it Positive!

Keep it Simple!

AVOID Flight, Fright, or Fight... they waste your time!

Communicating - Talking

First -

ALWAYS use the **positive physical approach!**

Then -

- Pay attention to the **THREE** ways you communicate

1 - How you speak

- **Tone** of voice (**friendly** not bossy or critical)
- **Pitch** of voice (**deep** is better)
- **Speed** of speech (**slow and easy** not pressured or fast)

2 - What you say

THREE basic reasons to talk to someone

1 - To get the person to **DO something** (5 approaches to try)

- 1 - give a short, direct message about what is happening
 - 2 - give simple choices about what the person can do
 - 3 - ask the person to help you do something
 - 4 - ask if the person will give it a try
 - 5 - break down the task - give it one step at a time
- ** only ask "Are you ready to..." If you are willing to come back later **

2 - Just to have a **friendly interaction** - to talk to the person

- ◆ go slow - Go with Flow
- ◆ acknowledge emotions - "sounds like..., seems like..., I can see you are..."
- ◆ use familiar words or phrases (what the person uses)
- ◆ know who the person has been as a person what s/he values
- ◆ use familiar objects, pictures, actions to help & direct
- ◆ be prepared to have the same conversation over & over
- ◆ look interested & friendly
- ◆ be prepared for some emotional outbursts
- ◆ DON'T argue... - BUT don't let the person get into dangerous situations

REMEMBER - the person is doing the BEST that s/he can

AND GO with the FLOW!

3 - Deal with the person's **distress or frustration/anger**

- ◆ Try to figure out what the person really **NEEDS or WANTS** ("It sounds like..." "It looks like..." "It seems like..." "You're feeling...")
- ◆ Use **empathy** not forced reality or lying

- ◆ Once the person is listening and responding to you **THEN** -
 - **Redirect** his attention and actions to something that is OK **OR**
 - **Distract** him with other things or activities you know he likes & values

Always BE CAREFUL about personal space and touch with the person especially when s/he is distressed or being forceful

3 - How you respond to the person

- ◆ use positive, friendly approval or praise (short, specific and sincere)
- ◆ offer your thanks and appreciation for his/her efforts
- ◆ laugh with him/her & appreciate attempts at humor & friendliness
- ◆ shake hands to start and end an interaction
- ◆ use touch - hugging, hand holding, comforting **only IF** the person wants it

If what you are doing is NOT working -

- **STOP!**
 - BACK OFF - give the person some space and time
 - Decide on what to do differently...
 - *Try Again!*

Key Points About 'Who' the person is....

- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a 'detail' or a 'big picture' person
- work history - favorite and most hated jobs or parts of jobs
- family relationships and history - feelings about various family members
- social history - memberships and relationships to friends and groups
- leisure background - favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs - dislike of music or songs
- hot buttons & stressors
- behavior under stress
- what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful

Personal History

Areas to Explore	What Did You Find Out?
Preferred Name	
Preferred Hand	
Living Situations & history (where are you from today & originally, who do & did you live with, what type places did you live in (house, apt, farm...))	
Marriage history & status (who's involved, has been involved, and how do you feel about them?)	
Family history & membership (who's who and how do you feel about them? Think about several generations....)	
Work history (what jobs have you had in your life? How did you feel about them? What are some jobs you would have loved to do, but never did?)	
Leisure history (what do and did you do for fun and in your spare time? How do you feel about 'having fun'? What would you like to do if you had the money? time? Skill?)	
Spiritual history (what religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)	
Personal care practices & history (eating habits, sleeping habits, grooming habits, bathing habits...)	
Time Use History (schedules & routines.... When do you and would you like to do things?)	
Important Life Events (what are some things that were very important to or happened to you? Do others know about these events?)	
Hot Buttons (what are things/activities /topics/ actions that tend to upset you?)	
Chill Pills (what are things/activities/topics/ actions /people that help calm you?)	

Is this a Problem Behavior that NEEDS to be fixed?

Does the behavior put someone at RISK?

YES

NO

It's time to **PROBLEM-SOLVE!**

This is **not** really a **PROBLEM** behavior for the person with dementia. It may be irritating or embarrassing for the caregiver, but it is really a...
'SO WHAT' behavior

Learn to let it go!
Leave it alone!
Don't sweat the small stuff!

Describe the behavior in detail---

- **Where** does it happen?
- **When** does it happen?
- **Who** is involved?
- **How** does it start? Stop?
- **What** is said? done?

1st

Answer these questions---

- Could the level of dementia explain some of this behavior?
- Could how the person was approached or helped have some impact?
- Does the person have other medical or psychiatric conditions that might be active?
- Could personal history (work, leisure, family, religion, personality, routines...) play a role?
- Could the environment or cues in it be causing some of the trouble?
- Could the time of day or personal habits be a factor?

Then

BRAINSTORM
with the Puzzle Pieces

Come up with a PLAN of ACTION!

- decide on **what** to do
- decide **who** will do what
- decide **how** to do it
- decide **when** to start it & when to look again

Are things better?

NO

RETHINK & Problem solve again!

YES

CELEBRATE!