

# Why Do They Do That???



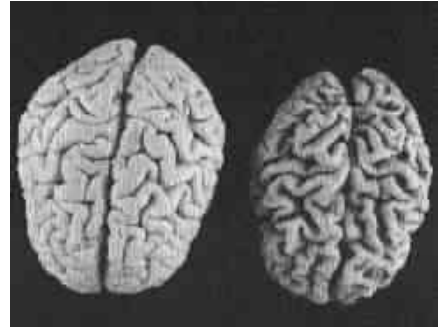
## Understanding the Symptoms and Behaviors AND How to Help – When to Get Help!

**Teepa Snow, MS, OTR/L, FAOTA**

- ◆ Dementia Care & Training Specialist, Eastern NC Chapter, Alzheimer's Association
- ◆ Counseling Associate, Duke University School of Nursing

## What is Dementia?

- ◆ It is NOT part of normal aging! It is a disease!
- ◆ It is more than just forgetfulness - which is part of normal aging
- ◆ It makes independent life impossible



### Dementia

- ◆ is an umbrella term that includes many cognitive loss conditions
- ◆ includes some reversible conditions - so should be checked out carefully

### Alzheimer's Disease -

- ◆ is the most common type of dementia
- ◆ is caused by damage to nerves in the brain and their eventual death
- ◆ has a expected progression with individual variations - about 8-12 years
- ◆ will get worse over time - we can't stop it!
- ◆ is a terminal disease - there is NO known cure at this time!

### Vascular Dementia (Multi-Infarct) -

- ◆ is caused by damage to the *blood supply* to the nerves in the brain
- ◆ is spotty and *not* predictable
- ◆ may *not* change in severity for long periods, then there are sudden changes

### Lewy Body Dementia -

- ◆ problems with movement – falls & stiffness
- ◆ visual hallucinations & nightmares
- ◆ fluctuations in performance – day/day

### Frontal-Temporal Dementias -

- ◆ Problem behaviors – poor impulse control
- ◆ Difficulty with word finding
- ◆ Rapid changes in feelings and behaviors

### Symptoms Common to Most Dementias... Over time...

- ◆ It affects a person's entire life...It causes the brain to shrink & stop working
- ◆ It steals memories - the most recent first, but eventually almost all...
- ◆ It steals your ability to use language ... leaves you with some 'skills'
- ◆ It steals your ability to understand what others mean & say
- ◆ It steals reasoning and logic
- ◆ It robs you of relationships
- ◆ It makes even the 'familiar' seem odd and scary
- ◆ It steals your ability to care for yourself and move around safely
- ◆ It robs you of impulse control - takes away emotional and mood control

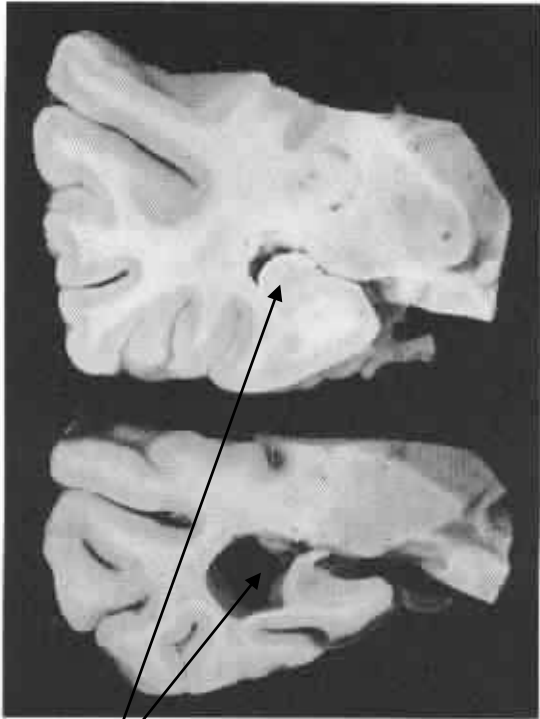
### Drug Treatment for Alzheimers

- ◆ Drugs to improve chemicals in the brain so nerve activity might happen
- ◆ Drugs to treat depression
- ◆ Drugs to control distressing hallucinations, severe paranoia, or unprovoked violence
- ◆ No vaccines or cures...yet
- ◆ No way to stop the disease...yet

### Prevention –

- Have a good family history for staying alert and 'with it' – genetics do play a part
  - ◆ Eat healthy & moderately (Heart-Smart)
  - ◆ Exercise your body --- 100 minutes/wk \*\*\*
  - ◆ Exercise your brain --- challenge yourself
  - ◆ Eat fish --- 1 time a week
  - ◆ Control your BP & sugar & weight
- \*\* consult your MD first

Normal



Alzheimer

*The ability to remember information...*

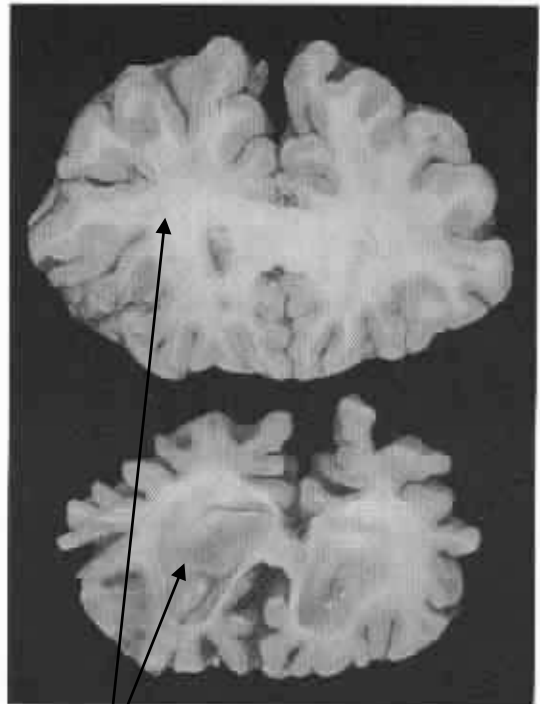
Normal



Alzheimer

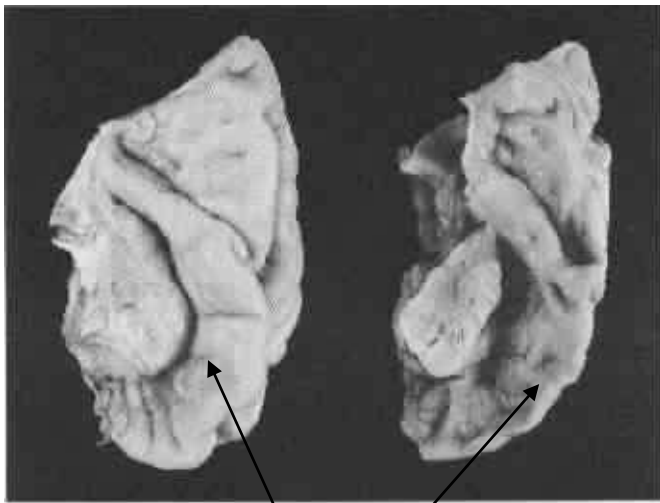
*The ability to use words and language...*

Normal



Alzheimer

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



Normal

Alzheimer

*The ability to understand what is being said...*

Reprinted with permission from: *A Broken Brain*. Dementia Education & Training Program, University of Alabama, 1995.

## **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 some awareness – "Just not right" – might blame others or self  
Can't remember 'new' rules, locations, plans, discussions, facts

### **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 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

## A Positive Physical Approach for Someone with Dementia

1. **Knock** on door or table - to get attention if the person is not looking at you & get permission to enter or approach
2. **Wave and smile** – look friendly and give the person a visual cue – make eye contact
3. Call the person by **name** OR at least say “**Hi!**” – pause then start approaching or let the person come to you, if s/he likes to be in control
4. Move your hand out from a wave to a greeting **handshake** position
5. Approach the person from the front – come in within 45 degrees of the center
6. **Move slowly** – one step/second, stand tall, don't crouch down or lean in as you move toward the person
7. Move toward the right **side of the person** and offer your hand - give the person time to look at your hand and reach for it, if s/he is doing something else – offer, don't force
8. Stand to the side of the person at arm's length – respect personal space & be supportive not confrontational
9. **Shake hands** with the person – make eye contact while shaking
10. Slide your hand from a 'shake' position to **hand-under-hand** position – for safety, connection, and function
11. Give your name & greet – “I'm (name). It's good to see you!”
12. **Get to the person's level** to talk – sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
13. NOW, deliver your message...

## Approaching When The Person is DISTRESSED!

### **TWO CHANGES –**

1. *Look concerned* not too happy, if the person is upset
2. *Let the person move toward you, keeping your body turned to the side* (supportive – not confrontational)
3. After greeting... try one of *two* options...
  - a. “Sounds like you are (give an emotion or feeling that seems to be true)???”
  - b. Repeat the person's words to you... If s/he said, “Where's my mom?” you would say “You're looking for your mom (pause)... tell me about your mom...”  
If the person said “I want to go home!”, you would say “You want to go home (pause)... Tell me about your home...”.

## BASIC CARD CUES – WITH Dementia

- Knock – Announce self
- Greet & Smile
- Move Slowly – Hand offered in 'handshake' position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly -make a 'nice' comment or smile
- Give your message... simple, short, friendly



# 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

## Having a Conversation

To Start Talking..... **LISTEN!**

### First \_

- **Recognize** the person and their situation or feelings (don't lie and don't be cruel...)
- **Use EMPATHY** – “it looks like...”, “it sounds like...”, “it seems like...” OR “This is really hard”, “This doesn't feel like the right place to be right now...”, “You really don't like what is happening”...

### Then \_

- ◆ If in *early stages* of the disease, gently offer 'orienting' information respecting what the person has said – NOT arguing reality...
  - ◆ “It's going to be a while before lunch...”, “The plan is for you to be here for tonight”, “ You are really missing your home, Tell me about where you come from...”
- ◆ If in the *middle or later stages* of the disease, figure out the meaning of the behavior or words ( repeat some of their words with a questioning tone to get started and when you aren't sure what they mean or 'where they are going with a conversation' SLOW DOWN and then se...
  - ◆ **Redirection** – same type of activity in a more acceptable manner, or with 'safer' materials, or in a safer space (Examples: cleaning out cabinets rather than the crash cart OR talking about her husband when they first got married versus why he is not here right now)
  - ◆ **Distraction** – changing to a different but equally valued activity (Example: looking for her cat that no longer exists to helping to put away dishes from the dish drainer and clean up the dining room)

### When having a conversation...

- use familiar phrases or words to help the person 'talk'
- use familiar objects or actions to give a focus for the interaction
- be prepared to have the SAME conversation over, and over, and over.....
- use your non-verbal interaction skills to show interest and engagement
- be prepared for unexpected emotional shifts and outbursts  
( *remember* - it's part of the disease)
- don't try to correct the person... GO WITH THE FLOW! - use empathy not reality!



## Communication - When Words Don't Work Anymore...

### Keys to Success:

- Watch movements & actions
- Watch facial expressions and eye movements
- Listen for changes in volume, frequency, and intensity of sounds or words
- Investigate & Check it out
- Meet the need

### *It's all about Meeting Needs...*

- Physical needs
- Emotional needs

### Probable Needs:

#### ***Physical***

- **In pain or uncomfortable**
- Thirsty or Hungry
- Need to pee or have a BM or already did & need help
- Constipated or impacted
- Tired
- Over stimulated or under stimulated
- Too hot or too cold
- Sick – medically ill – check for infections, physiological or physical causes

#### ***Emotional***

- Afraid
- Lonely
- Bored
- Angry
- Excited
- **In Pain**

### ***What Can You Do?***

- *Figure it out...Go thru the list*
- *Meet the need... Offer help that matches need*
- *Use visual cues more than verbal cues*
- *Use touch only after 'permission' is given*

**Connect** – Visually, Verbally, Tactilely

**Protect Yourself & the Person** – use Hand Under Hand & Supportive Stance techniques

**Reflect** – copy expression/tone, repeat some key words, move with the person

**Engage** – LISTEN with your head, your heart, and your body

**Respond** – try to meet the unmet needs, offer comfort and connection

**\*\*\* IF IT DOESN'T seem to be working – STOP, BACK OFF – and then TRY AGAIN – changing something in your efforts (visually, verbally, or through touch/physical contact)\*\*\***

# Types of Help - Using Your Senses

## **Visual -**



Written Information - Schedules and Notes

Key Word Signs - locators & identifiers

Objects in View - familiar items to stimulate task performance

Gestures - pointing and movements

Demonstration - provide someone to imitate

## **Auditory -**

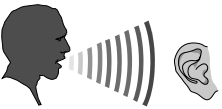
Talking and Telling - give information, ask questions, provide choices

Breaking it Down - Step-by-Step Task Instructions

Using Simple Words and Phrases - Verbal Cues

Name Calling - Auditory Attention

Positive Feedback - praise, "yes", encouragement



## **Tactile - Touch -**

Greeting & Comforting - handshakes, hugs, 'hand-holding'

Touch for Attention during tasks

Tactile Guidance - lead through 'once' to get the feel

Hand-Under-Hand Guidance - palm to palm contact

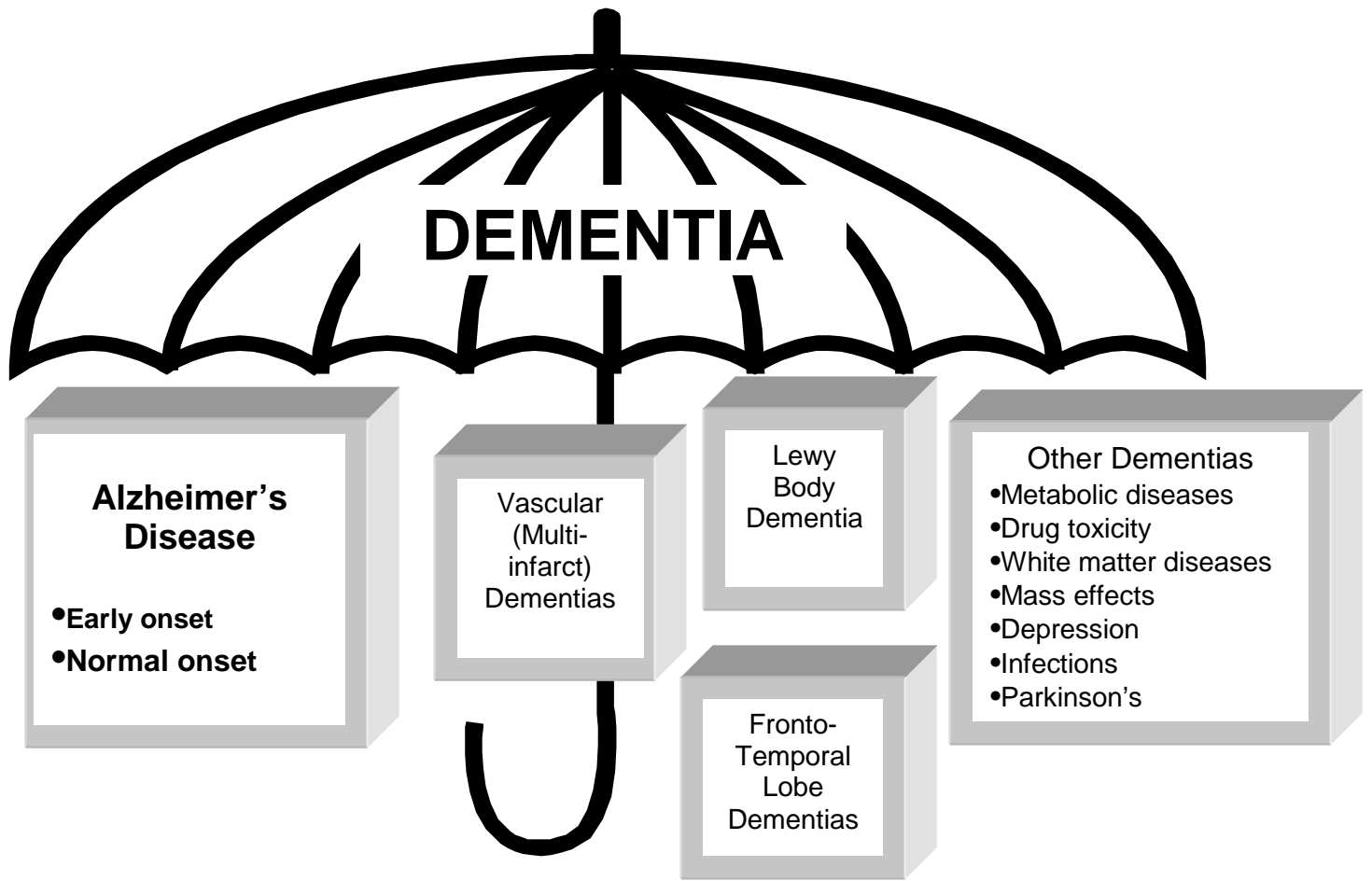
Hand-Under-Hand Assistance - physical help

Dependent Care - doing for & to the person



## Personal History

Areas to Explore	What Did You Find Out?
Preferred Name	
Preferred Hand	
<b>Living Situations &amp; history</b> (where are you from today & originally, who do & did you live with, what type places did you live in (house, apt, farm...))	
<b>Marriage history &amp; status</b> (who's involved, has been involved, and how do you feel about them?)	
<b>Family history &amp; membership</b> (who's who and how do you feel about them? Think about several generations....)	
<b>Work history</b> (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? )	
<b>Leisure history</b> (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? )	
<b>Spiritual history</b> (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?)	
<b>Personal care practices &amp; history</b> (eating habits, sleeping habits, grooming & bathing habits...)	
<b>Time Use History</b> (schedules & routines.... When do you and would you like to do things?)	
<b>Important Life Events</b> (what are some things that were very important to or happened to you? Do others know about these events?)	
<b>Hot Buttons</b> (what are things/activities /topics/ actions that really tend to upset you?)	
<b>Chill Pills</b> (What helps you calm down, what do you do when you are upset?)	



- Alzheimer's**
- New info lost
  - Recent memory worse
  - Problems finding words
  - Mis-speaks
  - More impulsive or indecisive
  - Gets lost
  - Notice changes over 6 months – 1 year

- Vascular**
- Sudden changes
  - Picture varies by person
  - Can have bounce back & bad days
  - Judgment and behavior 'not the same'
  - Spotty losses
  - Emotional & energy shifts

- Lewy Body**
- Movement problems
    - Falls
  - Visual Hallucinations
  - Fine motor problems
    - hands & swallowing
  - Episodes of rigidity & syncope
  - Nightmares
  - Fluctuations in abilities
  - Drug responses can be extreme & strange

- Frontal-Temporal**
- Many types
  - Frontal – impulse and behavior control loss
    - Says unexpected, rude, mean, odd things to others
    - Dis-inhibited – food, drink, sex, emotions, actions
  - Temporal – language loss
    - Can't speak or get words out
    - Can't understand what is said, sound fluent – nonsense words

# 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?

1<sup>st</sup>

Then

## 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?

**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!**