

Making Moments of Joy



It's What You Decide to Do as a Care Provider!

Teepa Snow, MS, OTR/L, FAOTA

- ◆ Dementia Care & Training Specialist, Positive Approach, LLC
- ◆ Consulting Associate, Duke University School of Nursing

What Does The Person DO? What Have They Done? OR.. What Won't They DO?

- Won't pick a health care POA or advance directives
- Won't allow financial guidance
- Won't go to the doctor
- Won't let anyone go with them to the doctor
- Won't see another doctor
- Has 'lost' important things – checkbook, money, papers, jewelry, purse, bills, receipts....
- Has accused others of taking or hiding 'lost' items
- Gets lost in the car
- Gets lost while out in the community
- Can't find the bathroom or other room in the house
- Gets lost in a familiar store or other place
- Burns pots or pans – can't make familiar foods correctly
- Puts spoiled food back in the frig – lets things set out or stores them in the wrong places then uses them
- Accidents while driving – fender benders, bumps in lots, 'dings'
- Problems with driving – citations for errors or speeding
- Breaks or 'messes up' equipment or appliances
- Does tasks with poor safety awareness
- Mis-takes medicines
- Calls you over and over
- Tells you the same thing over and over
- Calls others with the same message, over and over
- Does not do tasks that normally they did... shower, bathe, groom, change clothes, eat meals.... Unless you prompted
- Refuses to do things... shower, change clothes, shave, groom, take off coat, go to store, go to bed
- Refuses meds – 'don't need them', 'aren't mine', 'feel bad'
- 'Bad mouthing' you to others
- Making up stories – theft, abuse, neglect, visits, conversations...
- Resisting care – fights when you try to help (verbally or physically)
- Swearing & cursing
- Making 911 calls – without good reason
- Making 911 calls – with false reports
- Mixing day & night – up all night, napping during the day
- Mixing day & night – up for long stretches sleeping only a little

- Night time wakefulness after only a couple hours of sleep
- Shadowing – following you around constantly – doesn't want you out of their sight
- Eloping – going off on a mission – to another place, time, & situation
- Wandering – roaming off thru an unlocked or open door
- Getting 'into' things – handling and 'messaging' with things
- Shredding or tearing things apart
- Packing – 'going home'
- Moving things from place to place
- Collecting and gathering things – hiding them in strange places
- Taking things from restaurants or stores... from sugar packets or silverware, to 'shoplifting'
- Threatening caregivers – physically or verbally
- Undressing in public
- Being rude – saying things loudly or to others about their looks or actions, racial slurs, comments about others
- Feeling 'sick' – complaining about physical health – no illness that the MD can find
- Striking out at others – with some provocation
- Striking out at others – without provocation
- Seeing things & people that aren't there, but not scary
- Seeing things or people that scare or fright them
- Hear voices or sounds
- Feel things that you can't see or find
- Drinks a lot
- Eats a lot
- Won't eat or drink
- Urinating in the wrong places
- Hiding dirty or wet clothing or pads
- Stopping up toilets or sinks with soiled items
- Not recognizing who you are to them
- Mis-identifying other people who they 'should' know
- Talking like they are younger than they are
- Saying that you or others are out to hurt, kill, or harm them
- Not talking at all or very little
- Not making sense when they talk
- Others....



People with Dementia Are Doing the
 BEST They Can...
 These 'Behaviors' Are A Result of the
 Condition NOT the Person's Choice
 ANYMORE
 We are the One's with the BIG
 Brains!
 We Can Choose OUR Behaviors

Making Moments of Joy – It's What You Choose to Do as a Caregiver

Making Connections When Dementia Exists – Using What is Still There...

Recognize

- What makes your time with a person with Alzheimer's **special & unique**?
- ◆ The disease affects **all** aspects of the person's life!
- ◆ Some behaviors will seem *strange, unusual, rude, extreme, bizarre, or scary*.
- ◆ Family members are often *embarrassed & afraid* to have others see their loved one this way!
- ◆ People with Alzheimer's have lots of trouble using and understanding words and ideas
- ◆ New information that you share **CAN NOT** be absorbed, so they ask the same things over & over & they don't remember you were even there **and** accuse you of abandoning them!
- ◆ You don't get to use the techniques that are **MOST familiar and comfortable to you** to meet their spiritual, social, mental, or physical needs!

An Essential Thought –

Grieving is Ongoing for a Person and Family with Dementia because LOSS is gradual and progressive and irreversible!

- ◆ *Cognitive loss* – loss of ability to reason, problem solve, attend, plan... to be who they were...
- ◆ *Emotional loss* – loss of control, loss of regulation, recall of strong emotional memories... to act the way they should and did...
- ◆ *Social loss* – loss of relationships, loss of private versus public self, loss of social skills... talk and behave well...
- ◆ *Spiritual loss* – loss of ability to fulfill old roles in the community of faith, loss of ability to participate actively in the community, loss of ability to seek out spiritual help...
- ◆ *Physical loss* – slower than other losses, can be due to other causes, lots of injuries due to poor environmental awareness & slowed reactions, non-dramatic progression, eventual loss of movement & appearance of strong & primitive reflexes – ability to take in food and drink becomes a **BIG** issue toward the end of the disease

A Positive Approach - A Physical Approach that Helps –

ALWAYS---

- ◆ Come from the *front*
- ◆ Go *SLOW*
- ◆ Get to the *side*
- ◆ Get *low* - sit down
- ◆ Offer your hand
- ◆ Use the person's preferred *name*
- ◆ Wait for a response - *before you start talking or doing!*

To have a GOOD conversation –

- ◆ Introduce yourself – (“John, I’m Teepa, I came to see you this morning”) – No guessing games or forced relationships
- ◆ *Recognize* the person and their situation or *feelings* (“It looks like you have having a hard time...”)
- ◆ Respond to the *meaning* or emotion or intent of the message
- ◆ Offer concrete, *simple choices* (“Shall we walk or sing?”, “Do you want tea or coffee?”)
- ◆ Use familiar rituals, routines, words, phrases to help the person participate & “talk”
- ◆ Bring and use *familiar objects or actions* to help focus the interaction (pictures, pointing to things, toilet, glass of juice, dancing, hymnals, standing up or sitting down, smiling...)
- ◆ Be prepared to have the same conversation over & over & over... & enjoy it!
- ◆ Have *fun* and share *humor* **with** the person!
- ◆ Offer *physical comfort and care* when the person is distressed or afraid, not just words!
- ◆ Use your non-verbal behaviors to communicate interest & maintain contact – hold hands
- ◆ Use **redirection** when it is earlier in the disease process – shift the focus of the conversation
- ◆ Use **distraction** later in the disease process – focus on something else
- ◆ Be prepared for unexpected emotional shifts and outbursts... don’t argue or try to reason.
- ◆ **GO WITH THE FLOW** --- don’t try to correct the person & don’t make up lies!
- ◆ **Thank the person for taking time to be with you!** Tell them why you liked it!

To HELP Families – Be There!

- ◆ Make and maintain contacts during visits and phone calls or send notes or cards regularly
- ◆ Offer specific options for help when they are visiting
- ◆ Offer alternatives to help include their family member in the community
- ◆ Listen to how they are feeling and thinking – don't try to fix it or judge them
- ◆ Use empathy – not sympathy
- ◆ Let them know you have a 'understanding' of the disease and what it does to a 'person'
- ◆ **GO WITH THE FLOW!**

Know the Person

– Find Out Who They Have Been & Use It When You Visit

- Actively involved with people or quiet watcher?
- Tends to like to be alone or with others when distressed?
- Likes to DO things or likes to PLAN and TALK ABOUT things?
- Work history?
- Family members and relationships? (who are the people in the pictures)
- Free time interests?
- Favorite songs and hymns?
- Favorite stories, poems, readings, or scripture?
- Favorite routines, habits, or rituals?
- Hot button topics and 'words' or topics to avoid?
- Reactions to being touched? Respect it!

Respect WHO the person has been & Accept WHERE the person is now...

When Helping Physically to Do THINGS...

Remember to do things WITH the person, NOT TO the person!

Always CONNECT first

Visually
Verbally
Physically
Emotional
Spiritually

Take it slow – look for and wait for responses before moving on... Double check CUES!

Take a look around - Check out the environment or setting and set-up –

Is it clear what is supposed to happen?

Is it possible something is triggering the behavior or refusal?

Is it possible to create a stronger sense of privacy and competence?

Does the person feel OK, having you there?

Are you respecting intimate space & personal space?

If what you are trying is NOT working, STOP and BACK OFF!

Think about what might be getting in the way, change something, then try to re-approach

Make Sure – you are:

Limiting verbal information

Sending POSITIVE and FRIENDLY non-verbal cues

Taking your time to CONNECT

Letting the person know what you want – THINK about ONE step at a time

Show them what you want – model it, gesture through it, point to it...

Respecting personal & intimate space

ALWAYS, be willing to give up your agenda if you are having trouble getting the connection – you can always come back and try again, if they like you!

If it seems like they are getting upset with you...

Consider saying, “I’m sorry, I am bothering you, I didn’t mean to...”

Consider asking for a very ‘short’ commitment –

“Help me for 2 minutes & then I will leave”

Consider saying “Do you want to be alone?”

Stop talking or TRYING for a while and see what happens

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*

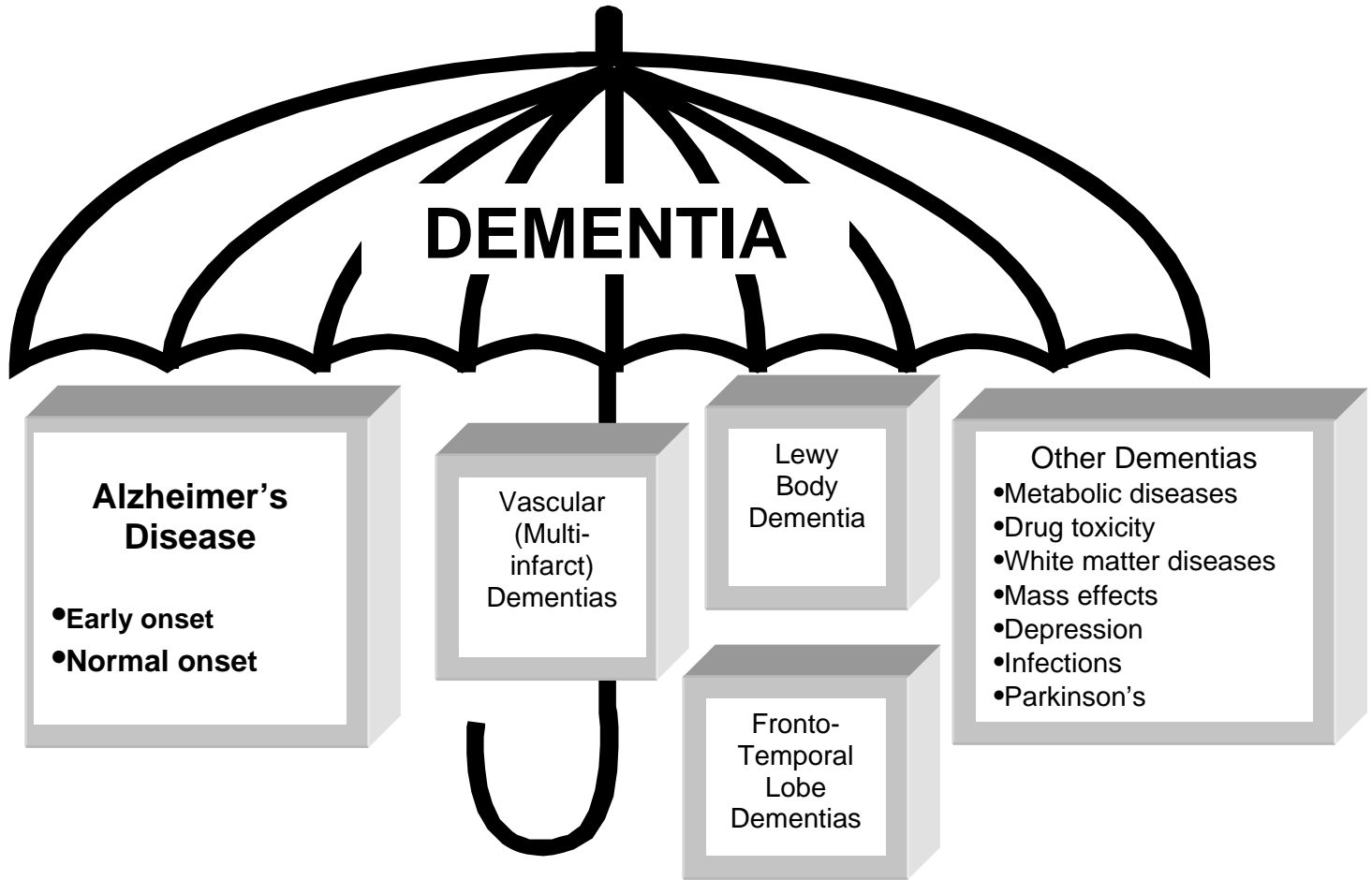
Touches and handles almost anything that is visible
Does not recognize other's ownership – takes things, invades space, gets 'too close'
Can still walk around and go places – 'gets into things'
Language is poor and comprehension very limited - does take turns
Responds to tone of voice, body language 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



- 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?

