Person-Centered Dementia Care
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Abilities remain at every stage of dementia
What’s the Deal?

- As brain cells deteriorate, changes can occur in:
  - Personality
  - Usual behaviors
  - Mood
  - Ability to think clearly
  - Ability to understand communication and to communicate clearly

- The frontal lobe controls impulses.
Challenges for People with Dementia

• Visual spatial deficits - depth perception
• Damage to the “filter” - between thought and action - say whatever they are thinking
• Damage to communication centers - word finding, word substitution and following a train of thought, trouble understanding the words spoken by others

• Decreasing coping strategies - decline in strategies that have helped them cope in the past
More challenges

- Damage to sleep/wake regulator of the brain
- Loss of directional map
- Loss of noise filter - noises are not prioritized. Multiple noises meld together and can be distracting and distressing
More Challenges

• Inability to multi-task

• Damage to emotional center- high risk for depression, as well as mood instability, lower threshold for becoming frustrated

• They often retain ability to read, but forget how to write

• Short attention spans
More Challenges

• Unable to play games with rules, such as Bingo
• Unable to control their emotions
• Do not trust caregivers who argue or who pretend to agree with them
Remember

WHO the person is, is as important as WHAT he or she has.
Think of it This Way:

• **Come help me (agitation):**
  - Slapping thighs
  - Yelling
  - Clapping
  - Screaming

  = something is wrong with me – do something!

• **Go Away (aggression):**
  - Hitting
  - Pinching
  - Biting
  - Swearing
  - Threatening

  = something is wrong with you – leave me alone!
What about Caregivers’ Reactions?

• 93% of communication is nonverbal!

• People with dementia rely more on nonverbal communication
• People with dementia may not be able to understand spoken words but can still pick up on non-verbal communication.

• You must watch how you approach people. They can read your facial expressions. If you are angry, they will pick up on that and often feel like you are angry at them.
Approach

• Also, watch your tone. Again they may not be able to understand exactly what you are saying but if you have an angry tone, they will pick up on it. Use a clear, low, warm, loving tone of voice.

• Get to know your residents. Get to know what usually works. For example, some people do well with come on, let’s go. Another way is to just extend your hand to them.

• SMILE!
Techniques for Communicating

• You must center* yourself before you can accept the emotions that are being thrown at you.

• Use nonthreatening factual words to build trust. Use “who,” “what,” “where,” and “how”—never “why”—to get the facts of a situation. Also, never use the word remember!

• Rephrasing- repeat what the person says, using his or her key words.
More Techniques

• Using polarity- people who have difficulty communicating with words will respond to questions that ask them to relate to the worst or best. Their attention span often increases when they talk about the extreme. For example, what hurts the worst?

• Use direct, prolonged eye contact. Caring is communicated through the eyes. For people in wheelchairs, the caregiver should bend or sit down.
More Techniques

• Use ambiguity to respond to a person who fails to make sense. If a person uses an invented word, use a vague pronoun. For example, “These tips don’t felangle” might be, “They don’t work? Did something go wrong?” “These wratches aren’t rubbable!” might be “Is there a problem with them? Can we fix it?”

• Link the behavior to the need. People express three basic needs: the need to be loved, the need to be useful, and the need to express feelings. A former salesman who is now 90 years old packs his suitcase every day. The caregiver relates this behavior to his needs and asks, “Do you want to get on the road, Mr. Jones? What do you sell?”
More Techniques

• Identify person’s preferred sense and emphasize that sense. To validate a person who frequently complains about the food, the caregiver should use words that evoke taste. “What does the food taste like, Mrs. Martin? Is it bitter? Too bland? When you were younger, did you like sweets? Did you do much baking?”

• Use music. Songs learned in early childhood become permanently imprinted on the brain. People who no longer recognize people and who are losing the ability to speak often remember songs.

• Use touch.
More Techniques

• Imagine the opposite. An 85 year old woman complains, “That man came back last night.” To validate her, the caregiver asks “Are there nights when he doesn’t come?” “Well, come to think of it, when you visited me the other night that man never once showed up. But soon as you left, and I was alone, there he was-plain as anything.”

• Reminiscing- “Did you always have trouble sleeping?” If looking for their mother- “What makes your Mom the best? Or “What is your favorite thing to do with your Mom?”
Meeting Example

During a risk management meeting several years back, one of the residents came to the door of the meeting room and was obviously very frustrated. I asked her if she was ok, and she said in an exacerbated tone, “I’m fine.” She came back several times after that asking about a meeting. We were all very focused on our meeting so we would quickly dismiss her. Then finally, when she came back again, she said, “I’m late for my meeting.” The light bulb went on and I said, “the meeting got cancelled Mildred.”

Her face lit up and she said, “that’s great, now I can go have a cup of coffee and enjoy my day!”

Sometimes the answers are simple, we just have to put ourselves in the shoes of the resident.
Consider the “Big Three”

• Care partner approach

• Environmental issues

• Physical health
Special Considerations

• Giving choice – must gauge stage

• Communication changes – community meeting, communicating history & routine

• Progressive nature – preferences will change

• Over-stimulation – watch for too much responsibility with too many steps

• Planning ahead – limited time frame, need visual cues

• Lack of initiative – how to fill the day
Returning Control

• Encourage the person to do as much for himself as possible—support his independence and ability to care for himself.

• Acknowledge the confused person’s anger over the loss of control in his life. Tell him you understand his frustration.

• Give him as many choices as you can throughout the day: what to wear, what to eat, how to spend the day
Get the Person’s Attention

• Avoid distractions: TV or radio

• Select their channel: people with dementia can only focus on one channel

• Position them with their back to distractions

• Maintain eye contact

• Call them by name, introducing yourself and who you are/what you do – EVERY time!
4 Step Introduction

1. Approach from front, getting \( \downarrow \) eye level, extending a hand

2. Say their familiar name (what makes them light up)

3. Say your familiar name & concrete statement about what you do

4. Say simple statement about what will happen next
Sample Introduction

1. Hello and extending a hand
2. “Good morning, Lois!”
3. “I’m Karen. I help you keep healthy”
4. Handing her the medication cup, “These are the pills for your back”

NOTE: End on a positive note to ↑ endorphins: “That blouse brings out the color of your beautiful blue eyes”
Elderspeak

- Often patronizing
- Resembles babytalk
Results of Elderspeak

- Sends a message that the person is incompetent
- Can start a negative downward spiral for older persons, who react with the following:
  - decreased self-esteem
  - depression
  - withdrawal
  - increase in dependent and negative behaviors
Ask Simple Answerable Questions

- Yes/no questions are best
- Don’t give too many choices
- Give a choice between two things, using visible cues when possible
Listen with Ears, Eyes & Heart

• Be patient

• Watch for non-verbal cues including facial expressions and body language

• OK to suggest a word, if you have given sufficient time for a response

• *Always strive to listen for the meaning and feelings that underlie the words.*
Break it Down

- Makes tasks more manageable
- Maintains independence for as long as possible
- Verbally or physically cue the steps
- Gently prompt by demonstrating the task or hand over fist
When the Going Gets Tough

• Try changing the subject or the environment. For example, ask him for help or suggest going for a walk.

• *It is important to connect with the person on a feeling level, before you redirect.* You might say, “I see you’re feeling sad—I’m sorry you’re upset. Let’s go get something to eat.”
Reassurance is Key

• When feeling confused, anxious and unsure of themselves, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.*

• Holding hands, smiling, touching, hugging (with consent) and praise may get the person to respond when all else fails.
Remembering the Good Ol’ Days

- Remembering the past often is a soothing and affirming activity.

- Avoid asking questions that rely on short-term memory, such as asking the person what they had for lunch.
Maintain Your Sense of Humor

- Use humor whenever possible, though not at the person's expense.
- People with dementia tend to retain their social skills and are usually delighted to laugh along with you.
Handling Difficult Reactions

- Requires creativity, compassion, patience, and above all: *flexibility*

- Difficult reactions = SOS call from a person with dementia
What we like to call behaviors......

- What we call behaviors are really reactions to pain, anxiety, depression, boredom.
- Reactions to unmet needs- cold or hot, hungry
- When we say someone is agitated, let’s actually describe what is going on. For example, they are frustrated with a neighbor who is being loud.
When is a “behavior” not a problem?

- If the behavior does not harm the person or others
- If the behavior is manageable and occurs only once or over a short period of time
- If the behavior can be easily redirected or stops with appropriate intervention
- If the behavior does not contribute to distress/suffering for the individual with the disease
Staff Actions Elicit Positive Responses

- Provide relaxing physical contact such as hand holding
- Apologizing if a resident complains of pain during a care activity
- Listening to resident concerns with empathy and compassion
- Providing reassurance that they are safe and you are there to help them
You Cannot Change the Person

• *Try to accommodate the reaction, not control the behavior.* For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

• *Remember that we can change our behavior or the physical environment.* Changing our own behavior will often result in a change in the person’s reactions.
Reaction is Triggered

- It might be something a person did or said that triggered a reaction
- It could be a change in the physical environment
- *The root to changing behavior is disrupting the patterns that we create.* Try a different approach or try a different consequence.
What Works Today May Not Tomorrow

- The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all.

- *The key to managing difficult reactions is being creative and flexible in your strategies to address a given issue.*
Boredom

• The level of desired activity depends on the individual. Think about prior lifestyles and how they have responded to being engaged in activities.

• Exercise- walking, dancing (chair or standing)

• Go outside- walk, work in the garden

• Develop activities based on past interests
Boredom Continued

• Initiate and schedule routine visits from friends
• Consider family meeting to discuss what has worked in the past
• Brainstorm productive activities: tearing up junk mail, gardening activities (pull weeds, scoop potting soil into pots, etc.), music and dance, sorting activities (nuts/bolts, earrings, pictures, cards, colors of puzzle pieces, silverware, etc.), adult coloring books, winding yarn into a ball, use of baby dolls, assist with food prep (tearing up lettuce, kneading dough, cut up tomato, etc.)
Wandering (Exploring)

- May be a behavioral expression of a basic human need: boredom, hunger, thirst
- May be in response to environmental irritants: noise, temperature, lighting
- May be in response to physical discomforts: pain, constipation, need to use the bathroom
- May be in response to psychological distress: fear, loneliness, insecurity
Advantages to Wandering

• Provides stimulation or social contact
• Helps maintain mobility
• Can increase conditioning and preserve strength
• Prevents skin breakdown
• Prevents constipation
• Can enhance mood
Disadvantages of Wandering

• If the person leaves the premises or enters an unsafe area or other resident’s space

• Injuries, including falls may occur

• Dehydration and/or weight loss (use something with pockets)

• Excessive fatigue

• Increased agitation
Joys of the Outdoors

- Fresh air
- Seeing and touching plants, flowers
- Feeling the sunlight on the skin
- Simply desiring to move about in the fresh air
- Daily walk
Regular Exercise

• Minimizes restlessness
• Maintains strength
• Improves appetite
• Reduces depression
• Increases endorphins
• Improves bowel function
Exit Seeking

- Can result from the desire to return to a secure, familiar home or former workplace
- May be trying to reconnect with family members
- May be following old habits such as leaving to pick up the kids at the bus stop
- May be drawn to the outside by a sunny day or a daily walk
Keeping them Safe

• A “do not enter”, “under construction”, or “hard hat area” sign may help keep a person from other people’s rooms.

• Put a black carpet piece or tile in front of doors - this may appear to be an impassable hole to the person with dementia due to spatial disorientation that occurs as the disease progresses.
Avoid 3-Dimensional Triggers

• Put away essential items such as the confused person’s coat, purse or sunglasses. Some individuals will not go out without certain articles – seeing them cues them to try to leave

• Avoid carrying your purse, car keys, or coats as you leave the neighborhood
Minimizing Unsafe Exploring

- Scheduled bathroom use according to the person’s usual pattern
- Engage in purposeful, meaningful activities
- Provide regular exercise and stimulation
- Take people outside regularly, preferably daily except during adverse weather
- Provide food and drink in a social environment
NO Personal Alarms

- Personal alarms DO NOT prevent falls
- Chair and bed alarms can be a burden to some people and lead to an increase in agitated behaviors. Some people fall trying to get away from the loud noise!
- Personal alarms that are audible may discourage all movement, not just unsafe attempts to stand or walk unassisted.
- Personal alarms are NOT dignified!
“Agitation”

- = range of behaviors associated with dementia, including irritability, sleeplessness, and verbal or physical aggression
- Can progress with the stages of dementia, from mild to more severe
- Triggered by a variety of things, including environmental factors, fear and fatigue.

*Most often, agitation is triggered when the person experiences “control” being taken from him.*
Possible Pre-Agitation Clues

- Hand picking
- Shedding actions
- Increased wandering, pacing
- Repetitive verbalizations
Environmental Triggers

• Too noisy
• Too cold/hot
• Too crowded
• Too large/small
• Too cluttered
• Over stimulating?
• Unfamiliar
• Is TV appropriate?
The Comfort of Routine

• Maintain structure by keeping the same routines

• Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories. Pics of residents’ and their families out

• Activities that provide purpose and pleasure throughout the day
Repetitive Speech or Actions (Perseveration)

- May repeat a word, statement, question or activity over and over
- Usually harmless for the person
- Can be annoying and stressful to caregivers
- Often is triggered by anxiety, boredom, fear or environmental factors
Calming Interventions

• Provide plenty of reassurance and comfort, both in words and in touch.

• Try distracting with a snack or activity.

• Avoid reminding them that they just asked the same question. Try ignoring the reaction or question and distract the person into an activity.

• Don’t discuss plans with a confused person until immediately prior to an event.
Paranoia

Suddenly suspicious, jealous or accusatory

- What the person is experiencing is very real to them
- Do not argue or disagree
- Don’t take it personally – due to short term memory loss, they do not remember who you are or that you are there to help them
“Stolen” Items

• Help them look for the object and then distract them into another activity.

• Try to learn where the confused person’s favorite hiding places are for storing objects, which are frequently assumed to be “lost.”

• Avoid arguing – reassure that the person is safe.
Hallucinations and Delusions

Hallucinations (seeing or hearing things that others don’t) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses.

- Avoid arguing or trying to convince the person their perceptions are wrong.
- Keep rooms well-lit to decrease shadows
- Offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard
- Try to offer a distraction (snack, walk, activity)
Sundowning

- a state of increased restlessness, agitation, disorientation and negative reactions, which happen late in the day through the evening hours.
Reducing Sundowning

- Discourage inactivity and napping during the day (but don’t deny them a nap if they really want or need it)

- Find out what they like to do and provide them the tools to do it

- Plan smaller meals throughout the day, including a light meal, such as half a sandwich, before bedtime

- Giving her a job such as folding baby clothes, setting the table, dusting, etc. to feel useful
Shhh – Keep it Quiet

• Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*

• Perhaps taking a stroll outdoors, playing a simple card game or listening to soothing music

• Sit with the person to reassure them of their safety
Lighting Makes a Difference

• Turn on lights well before sunset
• Close the curtains at dusk
• Install motion activated sensors to turn lights on as the person enters the area
• Be sure the nightlight in the person’s room is working

★ Doing these will minimize shadows and may help diminish confusion.
Rule Out Causes

• Is it due to pain?
• Is it due to medications?
• Is it hunger?
• Is it thirst?
• Is it constipation?
• Is it a need to go to the bathroom?
• Is it fatigue?
Making Bathing Pleasurable
Private and Personal

- People with dementia often have difficulty remembering “good” hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes.

- From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing.

- Bathing often causes distress for both caregivers and the person with dementia.
Hygiene Routines

All adults have developed a hygiene routine throughout their adult lives. This includes:

• Time of bathing: morning, noon, night
• Type of bathing: shower, bath, sponge
• Use of products: scented, unscented
• Frequency of bathing – as we age, we need less full body bathing due to dryness of the skin
Protecting Modesty

- Close doors and curtains
- Keep a towel/washcloth over her front, lifting to wash as needed
- Have towels and a robe or her clothes ready when she gets out
- ASK her what she wants!
- Undress ONLY in the spa
Bathing Environment

- Temperature of the room should be warm
- Water temperature should be warm, not too hot or too cold
- Lighting should be adequate, but low enough to be soothing
- Avoid letting water come down on their face – offer a washcloth before wetting down their hair
Providing Safety

- Never leave a person with dementia unattended in the bath or shower
- Have all the bath things you need laid out beforehand
- If giving a bath, draw the bath water first
- Reassure the person that the water is warm—perhaps pour a cup of water over her hands before she steps in
If they continue to fight you. . .

NOTHING will be gained by traumatizing the person with dementia by forcing them into a frightening situation!

And, someone could be injured!
Bathing Without a Battle

- Leave the person in bed
- Cover with a warm bath blanket
- Take another bath blanket moistened with no-rinse soap and warm water
- As you slowly remove the bath blanket, replace it at the same time with the warm, moist towel/blanket
- Massage skin and dry
To Dress or Not to Dress

• Reduce the person’s choices by asking family to remove seldom-worn clothes from the closet

• After offering a choice of two outfits, lay out one article of clothing at a time, in the order it is to be worn

• Remove soiled clothes from the room

• Don’t argue if the person insists on wearing the same thing again
Sexual Acting Out

- Sexually inappropriate behavior, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behavior, may occur during the course of the illness.
- Remember, this behavior is caused by the disease.
- Identify what triggers the behavior.
- Watch your approach, appearance, and touch.
- Provide privacy when needed.
- Educate family and caregivers.
Cursing/Threatening

= expressions of anger or stress

• React by staying calm and reassuring
• Validate the person’s feelings
• Try to distract or redirect his attention to something else
• Try food, drink, bathroom, exercise, walk outside, or an activity of interest
Reminders

- Negative reactions are a response to feeling out of control, rushed, afraid or confused by what you are asking of them
- Break each task into steps and, in a reassuring voice, explain each step before you do it
- Offer as much choice as possible
- Allow plenty of time
- Find ways to have them assist to their ability in the process, or follow with an activity that they can perform
Validation, Not Reality Orientation

Validation is based on an attitude of respect and empathy and is based on these underlying beliefs:

- All people are unique and must be treated as individuals.
- All people are valuable, no matter how disoriented they are.
- There is a reason behind the behavior.
• When more recent memory fails, older adults try to restore balance to their lives by retrieving earlier memories. When eyesight fails, they use the mind’s eye to see. When hearing goes, they listen to sounds from the past.

• Painful feelings that are expressed, acknowledged, and validated by a trusted listener will diminish. Painful feelings that are ignored or suppressed will gain strength.

• Empathy builds trust, reduces anxiety, and restores dignity.
Validation, not reality orientation

• This concept is based on validating where a person is at currently, not orienting them to current time and place.

• For example, if a person is asking about their mother, we should not say, “your mother has been dead for over 20 years.” Instead we should ask questions about her mother and reminisce. Engage in conversation with her, make it a bonding moment.
Resources

• Feil, N.; *The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer’s-Type Dementia*; Health Professions Press; 1993

• Niedens, M.; *The Neuropsychiatric Symptoms of Dementia: A Visual Guide to Response Considerations*
Questions?