Kneehill Resources for Dementia Care

#1 Seniors Outreach Program

Terry Schlinker – Administrator

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Website: www.seniorso.ca



#2 Kneehill Medical Clinic - Big Country Primary Care Network

Call to speak with or book an appointment with a Registered Nurse: **403-443-5522.** No referral required.



Dementia and Communication

Instructor: Welcome to salsa class! Who's ready to learn how to dance?

Me, hiding a bag of tortilla chips: There's been a misunderstanding.

- Communication is: 55% body language (visual), 38% tone and pitch (sound),
 7% what we actually say (words)
- Communication Tips:
 - Use a caring approach/attitude
 - Allow at least 10 seconds for a response
 - Use touch when appropriate to keep attention (hand under hand)
 - Present one idea at a time
 - Use orienting labels and names often
 - Maintain routines
 - Include the person in conversations about them
 - Ask the person how they want to help
 - Use gestures and non-verbal cues (facial expression, hand gestures)
- Try not to:
 - Argue
 - Ask questions that rely on memory or are open-ended
 - Rush them for an answer
 - o Tell them they "Can't" do something
 - Be condescending
- Rather than trying to bring the person with dementia back to our reality, it
 is more positive to enter their reality. Ask questions to find out where in
 time they are.
- Tools to help:
 - Music: Develop a personalized play list- what were their favorite songs? What do they respond to?
 - Memory Books: Designed as a chronological history of the person.
 Include letters, postcards and other memorabilia, also pictures with labels and descriptions. Only 2-3 items per page. Include life events (marriage, children, accomplishments, immigration, etc).
 - My Life Story- to assist with out of home care giver connections-Include:
 - I am.../I was.../I did... (List Major Life Achievements and Accomplishments)
 - I always... (Identify Life-long Habits that would help provide care)
 - Family, friends and pets who are important to me are: (List names and relationships, both current and past)
 - My special memories of home are (specify)...

- My favorite memory(is) of time with... (family, friends, pets) is/are...
- My personal preferences when helping me with my care include: examples: sleeping position; food/beverage
- I like talking about...
- I like it when others ask me... (for..., about....)
- When I am upset, I respond well to ...
- My favorite traditions, holidays, seasons are...
- I always celebrate...(describe)

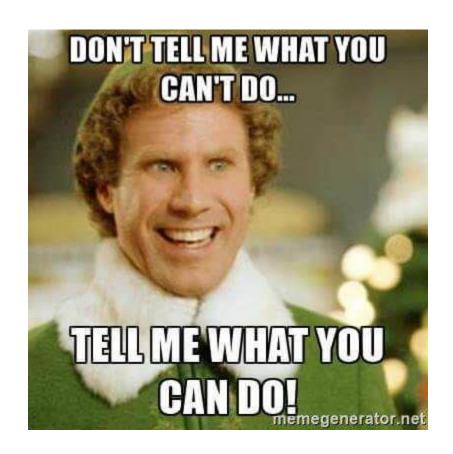
The life story bullets can be answered on a sheet of paper and posted in the home so when caregivers come in (ex. Home care), they can provide more patient centered care based on the information you have provided.

Book recommendation:

Keeping Love alive as memories fade by Gary Chapman

Helpful Tool: Communication Cards

Dementia and Everyday <u>Skills</u>



Dementia regresses the brain similar to how a baby's brain progresses

- The left side of the brain controls:
 - o Logic
 - Language, speech, comprehension
 - Motor control of the right side
 - Analysis and calculations
 - Timing and sequence
 - Recognition of words/numbers/letters
- The right side of the brain controls:
 - Music, poetry, prayer
 - Motor control of the left side of the body
 - Creativity
 - Spatial Ability
 - Context and perception
 - Recognition of faces, places and objects

Left side is attacked more quickly and more devastatingly than the right. A person living with dementia starts functioning more and more out of the right side.

Abilities that change:

REMEMBER: dementia is fluid- Abilities shift moment to moment and day to day

- Visual and spatial perception: no longer able to recognize people/places or identify objects, difficulty walking up stairs, difficulty concentrating/shorter attention span
- Communication: Word finding and comprehension abilities decrease,
 Miss 1 of every 4 words, No longer hear consonants, slower
 processing time, unable to make needs known verbally
- How you remember details: Difficulty processing/storing and retrieving information, physically getting lost on the way to somewhere familiar, Getting lost in a place or time (unsure whose house you are in/ unsure what year or season it is)
- o Different Abilities at different points in the day
- Lack of social awareness or socially inappropriate behavior: Right side
 of brain stores music, poetry and prayer- most likely to stay intact.
 Right side also stores "forbidden words" (swear words, racial slurs,
 sexuality and ugly words). Getting upset will make the situation

- worse. Speak using your emotions- it embarrasses me when you say that.
- Difficulty in planning, initiating, organizing and decision making: they stop doing activities that once gave their life meaning, no longer do basic or necessary tasks (ex. eating a meal left out for them), cannot do 2 tasks at once, overwhelmed with a task so they won't start it at all, cannot plan for the future
- Physical abilities and body functions: decrease in muscle coordination, ability/quality of sleep, eating/chewing/swallowing, toileting, fine motor skills
- Recall and inability to learn new skills: doing things and then deny they did it (no recall), unable to learn new skills
 - Normal aging- forget and then recall if reminded or it "pops" into your head
 VS
 - Not-normal aging- forget and absolutely no recall no matter the prompts

Teepa Snow's Gemstone Model



Every Gemstone is Beautiful and Unique

Each Gemstone is cherished BECAUSE of its flaws and Uniqueness not in spite of them.

Sapphire

Healthy brain- true blue! I can learn new things and habits although it may take some time. I am able to remember plans and information.

Diamond

Overall, my cognition is clear and sharp. When happy and supported, I am capable and shine. When distressed, I can be cutting and ridged and may see your help as a threat.

I have trouble seeing other points of view and may become less aware of boundaries or more possessive about my relationships, personal space, and belongings.

I have many facets so people see me differently depending on the situation. I can socially engage and have good cover skills. People will vary in their awareness of what is happening to me. I want to keep habits and environments as they always have been even if they are problematic for me or others. I am often focused in the past, personal values, or finances. I will need help to make changes in my life; it's hard for me.

<u>Skill level</u>: like familiar things and dislike change, live by habit and routine, start to have vision changes (scuba vision), word finding problems, slower to understand, can be repetitious, may get lost in unfamiliar places, focus on the past more than the present

Emerald

I am flawed: it is part of being a natural Emerald. I tend to be focused on what I want or need in this moment and may not be aware of my own safety or changing abilities.

I can chat socially, but I typically miss one out of every four words and cannot accurately follow the meaning of longer conversations. I won't remember the details of our time together, but I will remember how your body language and tone of voice made me feel.

I may hide or misplace things and believe someone has taken them. My brain will make up information to fill in the blanks which makes you think I am lying. If you try to correct me or argue I may become resentful or suspicious of you. I am not always rational, but I don't want to be made to feel incompetent.

My brain plays tricks on me, taking me to different times and places in my life. When I am struggling I may tell you "I want to go home". To provide the help and

assistance I need you must go with my flow, use a positive, partnered approach, and modify my environment.

<u>Skill level</u>: Emeralds are green and green means GO! Emeralds are flawed but don't know they are- they feel YOU are the problem, don't point out the flaws it will upset me, I like to start tasks but I don't finish them, could be missing 1 of every 4 words, tone and pitch really matter to me, I repeat phrases and get stuck in social chit chat

<u>Amber</u>

Like a particle trapped in an amber, I am caught in a moment of time. It may surprise you how I take in the world around me. I may not know or see you as a whole person. I react to you based on how you look, sound, move, smell & respond to me.

I like to do simple tasks over and over and may need to repeatedly move, touch, smell, taste, take or tear items apart. While it may frustrate and exhaust you, it soothes me. I don't recognize danger: you will have to safeguard my environment.

I'm intolerant to discomfort because my mouth, hands, feet and genetalia are highly sensitive due to changes in my nervous system. Therefore activities like eating, taking medications, mouth care, bathing, dressing, and toileting may distress me. Please notice my reaction and stop if I am resisting. I can't help myself and one, or both of us, may get emotionally and/or physically hurt. If this happens with me, wait a few minutes, connect with me again, and then try a different approach.

<u>Skill level</u>: NO caution/safety awareness, wants instant gratification- I want it now!, binocular vision, takes words out of context, repetitive language, less fine motor skills but retains their strength, cannot discern between old and new friendships, if I'm not comfortable in a place I will try and leave, time awareness-only this moment in time matters to me

Ruby

As the deep red of a ruby masks detail, my obvious losses make my remaining abilities harder to notice. Although my fine motor skills have become very limited, remember I am able to move and do simple things with my hands. You will need to anticipate, identify, and respond to all of my needs, even though I may not be aware of them. Plan to create a supportive environment, help with

the details of care, and structure of the day. Just as a crossing guard directs traffic, you will need to guide my movement and transitions.

I can rarely stop or start on my own and switching gears is a challenge. Move with me first, then use your body to show me what you want me to do next, going one step at a time. Hand under Hand assistance help me to feel safe and secure and to know what to do.

Danger is a part of my life due to losses in visual skills, chewing abilities, balance, and coordination. You can reduce risks to me, but not eliminate them. I can still have moments of joy when you are able to provide what gives me pleasure. Skill level: Red-I have STOPPED- all my fine motor skills have stopped (eyes/fingers/mouth/feet), I still retain big movements and I still have my strength, I still have RHYTHM! I like deep pressure and I like to hold things, I have significant balance changes, I may still respond to social chit chat or the sound and tone of your voice, I have limited environment awareness and very little time awareness- all I focus on is this moment, I also have very little situational awareness- I just know how I feel in that moment.

Pearl

While hidden like a pearl in an oyster shell, I will still have moments when I become alert and responsive. I am near the end of my life.

Moments of connection create a sense of wholeness and value between us. Use our time together not to just provide care, but to comfort and connect with me. To help me complete my life well, it's important to honor my personhood when making medical decisions or care.

Pease don't talk about me as though I'm not here. I respond best to familiar voices and gentle rhythmic movements. I am ruled by reflexes and startle easily. My brain is losing its ability to control and heal my body.

Be prepared to see me having difficulty breathing or swallowing. My body may no longer desire food or drink as I prepare to leave this life. You greatest gift to me at this time is your presence – and connection. I still hear music, and may still respond to it.

<u>Skill Level</u>: I operate primarily out of reflex, I have lost my gross motor skills-I am trapped, vision changes- brief moments, I might look towards you, I may make sounds. I still have a strong grip and may be slow to let go, I respond only to comfort or discomfort and have virtually no time awareness. With the right care I can relax

Days VS Nights

I'm not an early bird or a night owl, I'm some kind of permanently exhausted pigeon.

Why can it be difficult to fall asleep?

- Depression: sleep disturbances are linked to depression. Sleeping less/lighter can lead to depression and depression can lead to sleeping less/lighter. Depression can cause anxiety- anxiety causes sleep disturbances. Depression medication may help but isn't as effective for PLWD. Exercise has been proven to be just as effective as medication. Depression does not "just go away"- it needs to be treated.
- Physical Activity and Diet: Eating healthy and staying active becomes harder with age and dementia. For PLWD lunches high in carbohydrates have a HUGE impact on sleep at night. Dementia causes insulin in the brain to drop: causing PLWD to actually crave junk food. PLWD do not taste food the same: they want stronger flavors (ie: sugar). Aim for at least 30 minutes of activity per day.

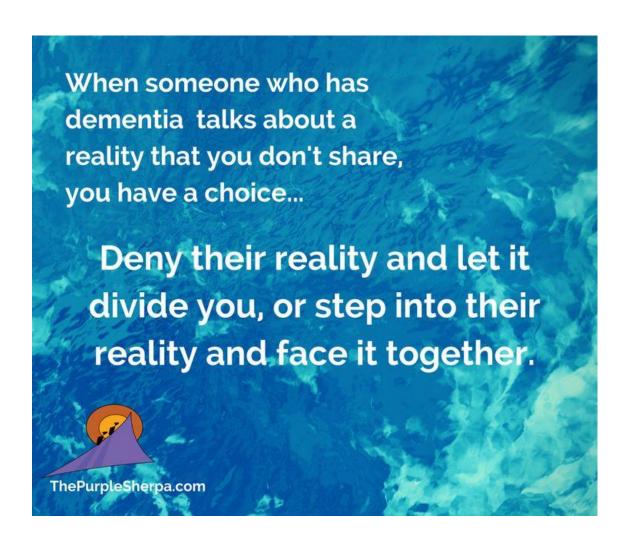
Tips to Try:

- Give lots of small snacks throughout the day. Finger food is best
- Have distractions planned.
- Pack in the protein and disguise the vegetables in the rest of the food.
- Avoid alcohol before a meal
- Switch to whole fruit- no juices or syrups
- A word on sugar
 - o Lack of sleep causes you to crave sugar
 - People with diets high in sugar sleep less & are more restless
 - o Sugar uses up a lot of our magnesium: which is needed for sleep
- Medications: Benzodiazepines and/or anti-psychotics are designed for short term use. They have very serious side effects such as increasing the risk of falls, confusion and aggression. The side effects can then increase sleep disturbances. Steroids and Beta-blockers inhibit sleep as well. Try environmental changes before medication.
- Circadian Rhythm: Our Circadian Rhythm has developed to wake us up in the morning & put us to sleep at night. Melatonin is produced by a gland in the brain the responds to light in the morning & dimming light at night. Morning light between 7am & 11am is very important for our bodies to produce melatonin. When we keep it dark during the day & turn lights on at night our brains are being reprogrammed to produce melatonin at the wrong times. Try to maintain a regular schedule

- Mental and Social Stimulation: Withdrawal from daytime activities leads to drowsiness, mood changes, depression, & agitation. Engagement is just as important to promote a good sleep as physical activity.
- Quality of Sleep: Brain waves decrease (for PLWD) in both Dreaming AND Non-dreaming States. While you sleep, your brain prepares for the next day, forming new pathways to help learn and remember information. Lack of Sleep can cause a PLWD to experience anger, impulsivity, mood swings, depression, or lack of motivation. For PLWD in the later stages, it is estimated that 40% of their time spent in bed, they are awake
- Those who cannot sleep may wander: Stay calm, do not argue, try to find out what they need, remind gently that it is night and "we should be in bed", do not restrain them, have appropriate activities to do (meditation apps, audiobooks, calming music, herbal teas, books or magazines)
- Try Non-drug treatments for sleep changes: Maintain Regular Times for Meals, Bedtime & Wake Times, get morning sunlight and daily exercise, avoid alcohol/nicotine/caffeine, look for and treat pain, provide dim lights and security objects (ex. Weighted blanket), Discourage Television and other screen uses during periods of wakefulness
- Vitamins that promote sleep: iron, magnesium, vitamin D, melatonin, B vitamins, chamomile, calcium and potassium, vitamin E
- Find out how the PLWD likes to sleep- what do they need physically and emotionally to fall into a good, peaceful sleep?
- Something to think about: Could you sleep well if:
 - o You didn't know where you were?
 - Strangers were entering your room at night, making you feel afraid?
 - If you were experiencing a delusion or dementia related hallucination?
 - Strange noises were making you unsettled?
 - o If you were angry or anxious: unable to relax?
 - o You didn't feel safe or secure?

A PLWD could be experiencing all of these things at night.

Your Reality Or Theirs??



Strategies for dealing with conflicting realities:

• Validation Therapy:

- o Recognize their emotions
- Reassure them- often they are looking for a place to feel comfortable. They want to go home because they feel safe and secure there. Pain could be the source of their distress- it is often under medicated in PLWD
- Give comfort- help them feel understood and supported
- Approach in a calm manner- use touch, light pressure on the inside of their palm can help calm them
- Avoid reasoning or too much explanation- keep it simple

• Re-Direct:

- Shift attention away from current situation to a more pleasant situation. Want them to feel cared for, listened to and safe.
- o 5 key elements
 - Take time to think (about your response)
 - Watch their non-verbal cues (and yours)
 - Be creative in your response
 - Remember what matters and forget the rest
 - Do not correct or argue

• Distract Them:

- o Focus on something else that won't cause upset
- Ask questions
- Suggest a snack/drink (healthy is better but if they have a special treat they like that's ok too)
- o Move to a new location/room- go outside if possible
- $\circ\hspace{0.1in}$ Start an activity- something tactile is good
- Use music- they will most likely remember music from their parent's era that they heard growing up or music from their teens/20's. Sing with them! Ex. You are my sunshine!

• Helpful Tips:

- Use details THEY provide
- Look for cues for why they are upset/distressed
- o Use your knowledge of the person
- Use your knowledge of the disease
- o Use your knowledge of the situation

• Confabulation:

They will (unknowingly) fill in the details because their brain does not remember. It is the next best thing to reality. Made up stories to fill any gaps in memory that only happens when you have a condition that affects your memory such as dementia. Ex. Someone is stealing from me, if they hide something and then have no recollection they hid it.

o 4 common accusations:

You stole my money!

Response: "Oh no is your money missing? I can see why you are upset. Can I help you look for it? Let's start over here and check your drawer.

Can also give them a bank book to "keep track" of their finances- often feel better if they can write it down Let them keep a wallet with a small amount of real \$

You stole my purse/glasses/dentures/hearing aid! Response: Oh no your hearing aid is missing? I can see why that would upset you. Let's look over here I thought I saw it earlier.

Try to find their favorite hiding places for items and check there first

Have duplicates (ex. More than one wallet or reading glasses that look the same) so you can give them what they are looking for if you can't find the original one.

You are poisoning me!

Response: I understand you are feeling afraid. I love you and would never let anything bad happen to you. Let's sit and eat together.

Eat meals together or take a bite off their plate to show its ok. Ask them to help you prepare/cook the meal

You are keeping me prisoner!

Response: sound like you want to go out- where do you want to go? I love that place too. What do you like best about going there?

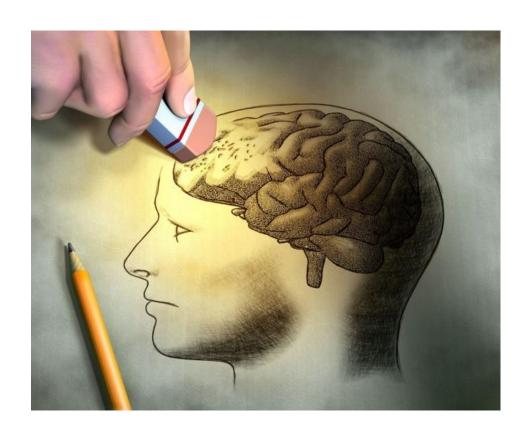
Try to actually go somewhere- even if it is just to another room. Go for a walk. Try to get outside.

Always important to still hear them out-listen to what they are saying.

• When is a lie not a lie?

- o When all of the above aren't working
- o When you are truly LIVING in their reality
- o When you are being exactly who and what they need in that moment

Responsive/ Reactive Behaviors in Dementia



Examples of Reactive Responsive Behaviors

Aggression: Verbal/Physical Racial Slurs
Badmouthing / Talking About Confabulation

Complaining / Whining Insomnia / Mixing Days & Nights

Constant Requests for Help Paranoia

Swearing / Ugly Words Refusing personal care

Grabbing People Screaming out Rummaging Toilet Issues

Exit Losing/Misplacing/Hiding Things

seeking/Elopement/Wandering Strange Noises
Agitation/Irritability/Anxiety Sundowning
911 calls Withdrawal

Restlessness' Sexual Language/Touching

The 10 Unmet Needs

<u>Physical</u>	<u>Emotional</u>
1. Intake	6. Anger
2. Energy	7. Sandness
3. Elimination	8. Lonliness
4. Comfort	9. Comfort
5. Pain	10. Boredom



BE SURE TO CONSIDER UNMET NEEDS AND TRIGGERS THAT MAY EXPLAIN BEHAVIOUR IN DELIRIUM OR DEMENTIA

www.DeliriumCareNetwork.com

Intake as an unmet need: Intake is anything that goes into you're body: food, liquid and medications.

<u>Medication issues</u>: refusing medication, skipping medication, wrong medication, not enough, incorrect taking if medication antipsychotic medication, over medicating and taking medications at the wrong time.

Energy as an unmet need: Energy as an unmet need comes into play because as dementia progresses, people are unable to self regulate. Identify things as: personal history, personal preferences, daily routine, what opportunities have they had to be active today, what stage of the disease are they in and what is their quality of sleep.

Elimination as an unmnet need: people don't like talking about going to the bathroom because it is PRIVATE!

<u>Tips to assist with toileting:</u>

- Remember that Toileting is a private issue & needs to be discreet
- Approach is everything
- Give Visual cues BEFORE Verbal cues
- Always do WITH never TO
- Misinterpretations of staff's actions (usually due to miscommunication) can possibly lead to Reactive/Responsive Behaviors of a sexual nature. Stay calm, and explain what you are doing
- Do not take their advances/comments personally. Remember it is a response to the ask being performed.

Comfort as an unmet need: You need to ask a lot of questions to find out what makes someone comfortable. When someone is uncomfortable, they can be mildly irritated up to physically aggressive. Comfort needs to be considered on both a physical and emotional level.

Visual intake changes comfort levels:

Scuba vision: Early to mid-stage dementia

<u>Binocular vision</u>: mid-stage dementia Monocular vision: late stage dementia **Pain as an unmet need:** The difference between a PLWD & a person living without dementia is that a person without dementia can recognize the pain they are experiencing. Do NOT confuse the ability to talk with the ability to recognize pain. Generally speaking, People WITH dementia receive ¼ LESS pain medication But 3X MORE anti-psychotics.

When looking for unspoken signs of pain in a PLWD, Look For:

- Face grimacing, moaning/crying, increased/decreased vocalization
- Gestures that indicate distress, guarding a body part
- Moaning with or without movement, limited ROM or slowed movement
- Restlessness, agitation, aggression, irritability, anger
- Withdrawing socially, self-isolation
- Lethargy, increase in sleeping and/or inability to sleep/waking up frequently
- Decreased appetite and increased confusion

Anger as an unmet need: The AMYGDALA is the part of the brain that is responsible for our perception of emotions such as ANGER, FEAR, SADNESS, PLEASURE, & the ABILITY TP CONTROL AGGRESSION. We need to have a complete Life Story before Responsive/Reactive Behaviors occur because we need a BASELINE of Behavior. The Frontal Lobe is responsible for regulating impulse control. People living with Dementia still have normal mood swings, pet peeves & triggers.

A PLWD can become angry or annoyed because of circumstances such as:

- Being around other people not of your choosing all of the time.
- People entering your room, particularly without knocking or permission
- Not having enough purposeful activity

Sadness as an unmet need: Sadness and depression is extremely common with a PLWD. Irritation is often overlooked as symptoms of depression. People with depression often experience anxiety and feeling of isolation. Up to 70% of PLWD experience depression at some point. Depression can cause: Increased forgetfulness, confusion & anxiety, making the symptoms of Dementia appear exaggerated. HOWEVER! Depression will most often respond to treatment! Dementia will not.

Connection

Connection is about meaningful interactions. Not simply being where other people are. People get the care they need to survive, but not necessarily what they need to thrive. Connection is not just about not being lonely. We need to connect on an emotional level. Offering to help is one way we can tell if someone is seeking a connection. It's not the activity that matters, it is the interaction that is important. Having a connection isn't always with a person. Sometimes we connect with a place or thing. Sometimes people need the opportunity to connect with themselves. To connect who they were THEN with WHO they are now.

PLWD are not attention seeking they are connection seeking!!

Scared as unmet need: a PLWD may no longer recognize situations and this may cause them to be scared.

<u>Some examples of things that causes a PLWD to be afraid:</u>

- Strangers entering their private spaces
- No knowing when their next meal will come
- Feeling trapped or locked in and not knowing where your family is.
- Having personal care performed by strangers
- Not being able to communicate your needs and make people understand
- Afraid of falling and loss of mobility in your hand and legs/feet

Boredom as an unmet need: a PLWD biggest complaint is boredom and loneliness, it is critical to provide opportunities for a PLWD to feel useful and engaged. Reactive Responsive Behaviors are most often tied to BOREDOME. RRB behaviors include: sundowning, resistive to care, agitation, paranoia & increased confusion. When people do not have enough meaningful activities to occupy their mind & body they start finding things to do because people are naturally programmed to do purposeful activities.

Example of engagement activities:

- ~Sorting jars of coins & buttons
- ~Pictures to place in albums
- ~Sharpening pencil/pencil crayon
- ~Music stations
- ~Cleaning items (vinegar & water), washing dishes
- ~Sorting seashells, jewelry, card, nuts & bolts, cutlery
- ~Coloring, easy crafts, puzzles,
- ~Folding laundry & preparing food, sweeping the floor
- ~Fidget toys, untying knots

Tips to engage PLWD in meaningful activities:

- Invite them to participate don't just assume they will Go, or say No
- Demonstrate how the activity happens
- Ask for "help" (could you sort these cards for me? I just don't have time.)
- Offer the person something to hold or touch
- Thank the person for helping! Offer choices "Would you like THIS or THAT?"
- Consider timing
- Focus on the PROCESS not the end result
- ~ A PLWD will not always remember what you have said, but they WILL remember how you made them feel.
- ~ The stronger the emotion attached, the stronger the memory.
- ~ When we see a RRB happening, stop & ask "What is CAUSING this Behavior?"

When working with Responsive/Reactive Behaviors there is one rule: APPROACH!!

Resources:

Tricia McKenzie-Tetz
Recreational Therapist
PAC Certified Dementia Educator
PAC Certified Dementia Behaviours Consultant
403-597-1370

Tricia.Tetz@AHS.ca

For more information about Teepa Snow's Gemstone model:

Teepa Snow's Website on Positive Approach to Care offers a lot of valuable information and insight.

https://teepasnow.com/about/about-teepa-snow/the-gems-brain-change-model/

Teepa Snow also offers a free phone app with all the information on the gems that Tricia talked about in her presentation and so much more.

For more support and resources please contact:

Kim Larsen and Lisa Orton

AHS Community Recreation Therapy

Drumheller, Hanna and Three Hills

403-820-7297