

*Changing the Culture of
Dementia Care
One Mind at a Time*

Positive®
Approach

GEMS®

Dementia **Aware**

Dementia **Knowledgeable**

Dementia **Skilled**

Dementia **Competent**

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July 27th from Eastern Time

<https://pasrr.org/event-4205305/Registration>

Networking with NAPP (NwN)

A Positive Approach to Care:
Dementia and PASRR Discussion

Presenters:

Beth A. D. Nolan, Ph.D

Director of Research and Policy and Trainer for Positive Approach® to Care

Discussion Facilitator:

Jean Kaske, Ph.D

Behavioral Consulting Services and NAPP Board Member

July 27, 2021 1:00 PM - 2:00PM EST

Join Meeting Here

Meeting ID: 976 1640 2731 Passcode: 389214

Dear Beth Nolan,

You are invited to the following [event](#):

Networking with NAPP - July 2021

When: 27 Jul 2021 1:00 PM, EDT

Where: <https://zoom.us/meeting/register/tJMrdu-srjktGdU0Bb5SBmauleKgdPbRbUBv>



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A Positive Approach to Care: Dementia and PASRR Discussion

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Differentiating Delirium, Dementia... Depression and other forms of Mental Illnesses

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Drugs That Can Affect Cognition:

Anti-arrhythmic agents

Antibiotics

**Antihistamines -
decongestants**

**Tricyclic
antidepressants**

Anti-hypertensives

Anti-cholinergic agents

Anti-convulsants

Anti-emetics

**Histamine receptor
blockers**

**Immunosuppressant
agents**

Muscle relaxants

Narcotic analgesics

Sedative hypnotics

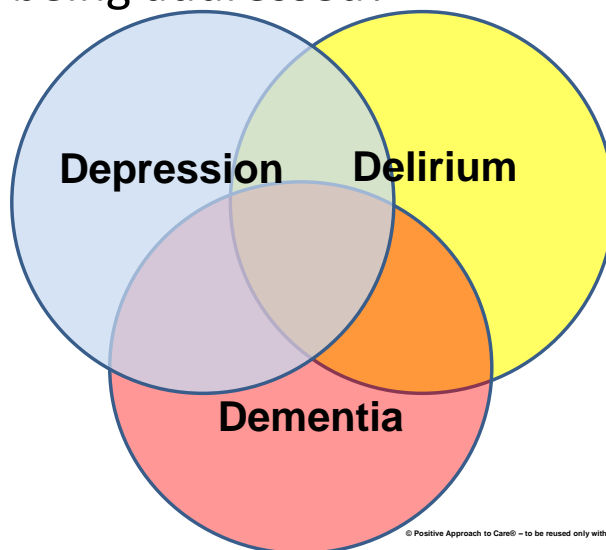
**Anti-Parkinsonian
agents**

Washington Manual Geriatrics Subspecialty Consults edited by Kyle C. Moylan (pg 15) – published by Lippencott, Wilkins & Williams , 2003

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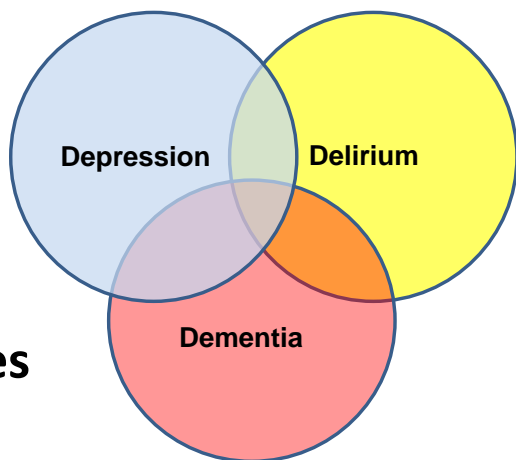
The Real Three D's

- NOT 3 clean or neat categories (MIXED together)
- Which 'D' is causing what you are seeing NOW?
- Are all three D's being addressed?
 - Immediate
 - Short-term
 - Long-term



What's What for Each D:

- Onset
- Hx & Duration
- Alertness & Arousal
- Orientation responses
- Mood & Affect
- Causes
- Treatment for the cause/condition
- Treatment for the behavioral symptoms



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Delirium



Delirium

- **Onset** – sudden. Hours to days
- **Hx & Duration** – ‘cured’ or ‘dead’ - short
- **Alertness & Arousal**–fluctuates, hyper or hypo-
- **Orientation responses**– highly variable
- **Mood & Affect**– highly variable - dependent
- **Causes**– physiological physical, psychological
- **Tx condition**– ID & Treat what is WRONG
- **Tx behavior**– manage for safety only – short term only, don’t mask symptoms

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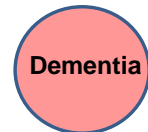
Depression



- **Onset** – recent. Weeks to Months
- **Hx & Duration**– until treated or death; months to years
- **Alertness & Arousal**– not typically changed
- **Orientation responses**– “I don’t know,”
“Why are you bothering me with this?”,
“I don’t care.”
- **Mood & Affect** – flat, negative, sad, irritated
- **Causes** – situational, seasonal or chemical
- **Tx of condition** –meds, therapy, physical activity
- **Tx of behavior** – schedule & environmental support, help – combined with meds

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Dementia

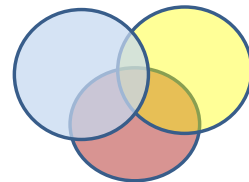


- **Onset** – gradual – months to years
- **Duration** – progressive till death
- **Alertness & Arousal** – gradual changes
- **Orientation responses** – right subject, but wrong info, angry about being asked, or asks back
- **Mood & Affect** – triggered changes
- **Causes** – brain changes – 60-70 types
- **Tx of condition** – chemical support; AChEIs & glut mod
- **Tx behavior** – environment, help, activity, drugs

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Determine 1st— Is this Delirium?

- Delirium can be dangerous & deadly
- Get a good behavior history – look for change
- Assess for possible PAIN or discomfort
- Assess for infections
- Assess for med changes or side effects
- Assess for physiological issues – dehydration, blood chemistry, O₂ sat
- Assess for emotional or spiritual pain



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Be Aware of Acute Confusion

Delirium

Symptoms

- Suddenly worse
- Very different
- Very agitated
- Having hallucinations
- More extreme
- Harder to work with
- More confused
- S/he's "just not like this..."

LISTEN...

Causes in Elders...

- Meds: effect, side effect, interactions, sudden stop, mis-taking
- Infection: UTI, URI, sepsis
- Medical condition is worse
- Dehydration
- Sleep deprivation: poor sleep
- O₂ regulation: deprivation/imbalance
- New place; new restrictions
- Pain or discomfort: impaction, broken bone, cancer

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More Causes of Delirium:

- Sensory deprivation: vision, hearing, balance
- TIAs or little strokes in brain
- Alcohol use
- New Onset Illness: diabetes, hypothyroidism
- Nutritional Issues: intake or processing problems
- Anesthesia: post-surgical



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Confusion Assessment Method:

Delirium

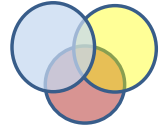
1. Acute Onset or Fluctuating Course
and
2. Inattention
and
3. Disorganized thinking
or
4. Altered Level of consciousness

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.

Inouye, S., van Dyck, C., Alessi, C., Balkin, S., Siegel, A. & Horwitz, R. (1990). Clarifying confusion: The confusion assessment method. *Annals of Internal Medicine*, 113(12), 941-948.

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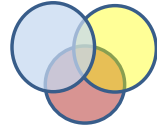
Additional Screening:



- First use your self and your approach
- Quick chart review
- Then:
 - FROMAJE
 - AD-8 Interview
 - Animal fluency: 1 minute # of animals
 - Clock Drawing: 2 step
 - SLUMS: 7 minute screen

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FROMAJE:



- Function – score 1-3
- Reasoning – score 1-3
- Orientation – score 1-3
- Memory – score 1-3
- Arithmetic – score 1-3
- Judgment – score 1-3
- Emotional State – score 1-3

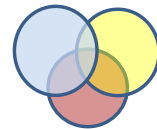
9 = intact, 10-14 = check on change/baseline? 15 or more further investigation is needed, especially if no diagnosis is noted

Not normal does not mean dementia, may be delirium or depression, or other health problem, sensory deficit, or ???

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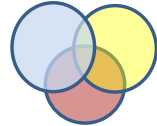
AD8 Dementia Screening Interview:

- Does your family member have problems with judgment?
- Does your family member show less interest in hobbies/activities?
- Does your family member repeat the same things over and over?
- Does your family member have trouble learning how to use a tool, appliance, or gadget ?
- Does your family member forget the correct month or year?
- Does your family member have trouble handling complicated financial affairs ?
- Does your family member have trouble remembering appointments?
- Does your family member have daily problems with thinking or memory?
- Scores: Changed, Not Changed, Don't Know



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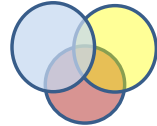
Animal Fluency:



- Name as many animals as you can
- Give one minute – (don't highlight time limit)
- Count each animal named (not repeats)
- Establish Baseline versus Normal/Not Normal
 - 12 normal for > 65 and 18 for <65
 - Compare you to you over time

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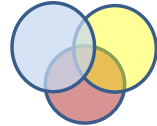
Clock Drawing:



- Provide a big circle on a blank sheet of paper
- Ask to draw the face of a clock and put in the numbers
- Watch for construction skills and outcome
- Ask to put hands on the clock to indicate 2:45
- Watch for placement and processing
- Scoring: 4 possible points
 - 1-12 used
 - Correct quadrants
 - Minute hand correct
 - Hour hand correct

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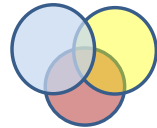
SLUMS:



- Orientation – day of week, month, state (3)
- Remember 5 items – ask later (5)
- \$100 – buy apples \$3 and Trike \$20
 - What did you spend? What is left? (2)
- Animal fluency (0-3) (<5, 5-9, 10-14, >14)
- Clock drawing (4) – numbers in place, time correct
- Number reversals (2) – 48 – say 84...
- Shapes (2) – ID correct, which is largest
- Story recall (8) – recall of info from a story – 4?s

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SLUMS - Rating



High School Education:

27-30 – Normal

21-26 – MNCD (MCI)

1-20 - Dementia

Less than High School:

25-30 – Normal

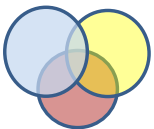
20-24 – MNCD (MCI)

1-19 - Dementia

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Determine 1st— Is this Delirium?

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- Assess for infections
- Assess for med changes or side effects
- Assess for physiological issues – dehydration, blood chemistry, O₂ sat
- Assess for emotional or spiritual pain

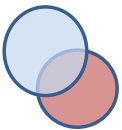


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2nd – Is it Dementia or Depression



- Depression is treatable
- Many elders with 'depression' describe themselves as having 'memory problems' or having 'somatic' complaints
- Look for typical & atypical depression
- Look for changes in appetite, sleep, self-care, pleasures, irritability, 'can't take this', movement, schedule changes



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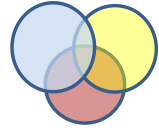
3rd – If it looks like a duck... swims like a duck...

- Explore possible types & causes
- Explore what care staff & family members know and believe about dementia & the person
- Determine stage or level compared with support available & what we are providing
- Seek consult and further assessment, if documentation does NOT match what you find out



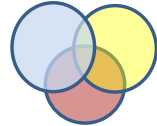
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Pain Screening



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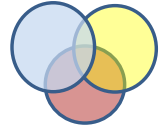
Pain Management Guidelines:



- Establish relationship
- Assume there will be pain
- Be alert: look, listen, feel for pain
- If 'it' would hurt you assume 'it' hurts them
- When there is a change in 'behavior', check out the possibility of pain first!
- Connect to the person before you try to 'fix' it
- Use acetaminophen regularly if possible, not prn

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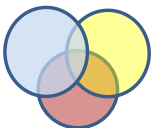
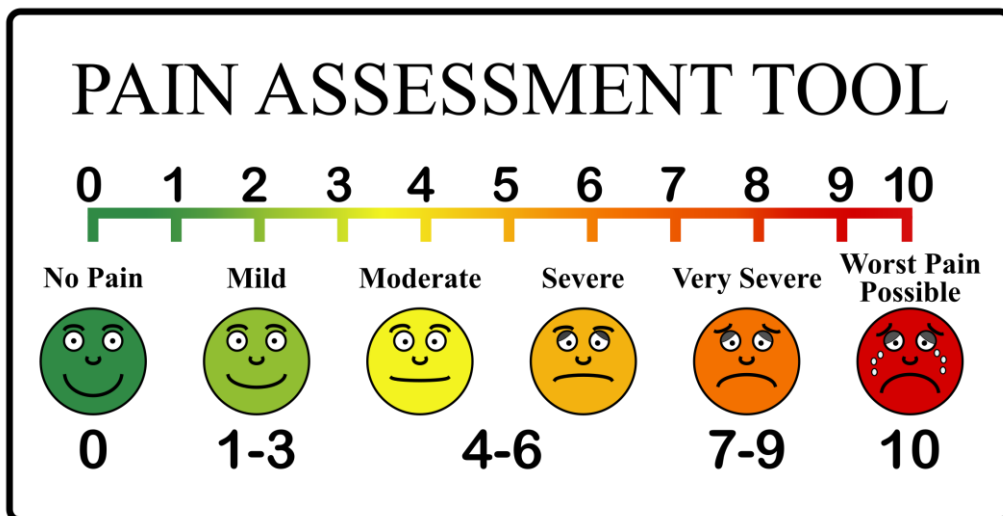
Guidelines for Pain Assessment:



- What you see, hear, feel
- Use of tools: early stages only (diamonds)
 - Visual
 - Pictures
 - Try to see what works, then use consistently

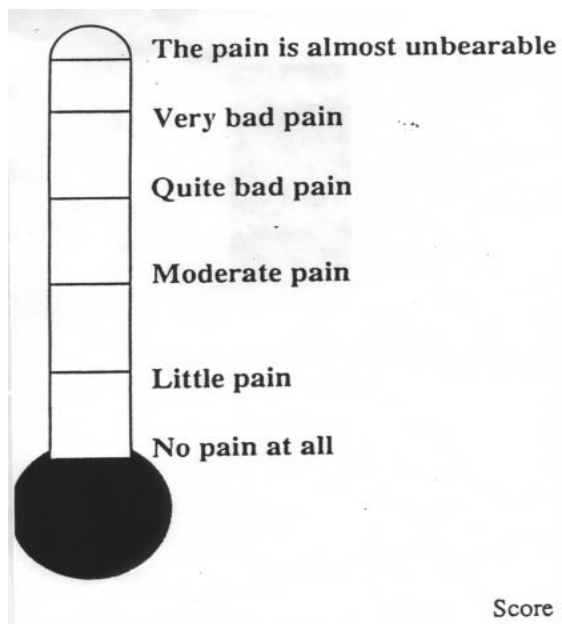
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Individualize Your Pain Scale:



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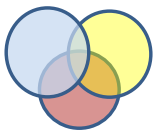
Pain Thermometer:



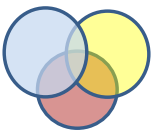
A vertical thermometer-like scale with a black bulb at the bottom and a vertical tube with seven horizontal segments. To the right of the segments are labels for pain levels. The labels from top to bottom are: 'The pain is almost unbearable', 'Very bad pain', 'Quite bad pain', 'Moderate pain', 'Little pain', and 'No pain at all'. The word 'Score' is written at the bottom right of the scale.

Pain Level	Score
The pain is almost unbearable	7
Very bad pain	6
Quite bad pain	5
Moderate pain	4
Little pain	3
No pain at all	2

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Remaining Screening Recommendations

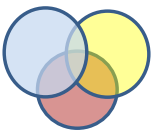


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Medications for Elders:

What works:

- Scheduling medications
- Providing for breakthrough pain
- Balance pain relief with function
- Using right class for the type of pain
- Monitoring for response: positive or negative



What doesn't work:

- Antipsychotics
- Anxiolytics
- Treating the symptoms, not the cause
- Over-responding to pain
- Ignoring medications as options

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Facilitating Communication with People with Brain Change



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Primitive Brain is in Charge of:



Survival:

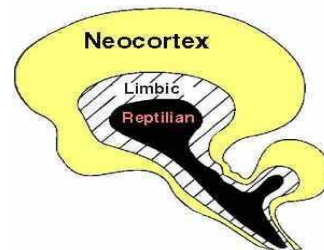
- Autonomic protective: Fright, flight, fight + hide or seek
- Pleasure seeking: Meeting survival needs and finding joy

Thriving – Running the Engine:

- Maintain vital systems: BP, BS, Temp, Pain, Oxygen
- Breathe, suck, swallow, digest, void, defecate
- Circadian rhythm
- Infection control

Learning New and Remembering:

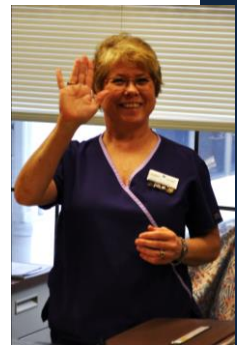
- Information
- Places (spatial orientation)
- Passage of Time (temporal orientation)



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Use the Positive Physical Approach™

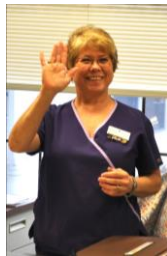
- Pause at edge of public space (6 feet out)
- Greet with your open hand next to your face, smile
- Call the person by name, if possible
- Move your hand into handshake position
- Approach slowly and within visual range
- Move from a handshake to Hand-under-Hand® position
- Shift into Supportive Stance on *their* side dominant side
- Get low. Stand & lean away, or kneel. Don't lean in
- Make a connection and wait for their response



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Positive Physical Approach™ in Pictures

1. **Stop** moving 6 ft out
2. **Greet:** “Hi (name)”,
with hand by face
3. Move **into a handshake**
4. **SLOWLY** come in from front



5. Move into **Supportive Stance** on their dominant side (sift body 90°s, like Peg)
6. Move into **HuH®**
7. **Get low** or lean away
8. Make **connection** (wait!)



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How Can We Become **Better** Communicators?

Let go of the past to be in the moment

Go with their flow

Be willing to try something new

Be willing to learn something different

Be willing to see it through another's eyes

Be willing to fail and try again

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How Can We Become **Better** Communicators?



03_Amber_Drinking with and Letting It Go-Martini

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Then, Connect Emotionally:

Make a connection

- **Offer your name:** “I’m (name) and you are...?”
- **Offer a shared background:** “I’m from (place) and you’re from...?”
- **Offer a positive personal comment:** “You look great in that!” or “I love that color on you.”

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Connecting Emotionally:

- Identify common interest
- Say something nice about the person or their place
- Share something about yourself and encourage the person to share back
- Follow their lead and listen actively
- Use some of their words back to keep the flow going
- Remember it's often the 'first time' for them, so expect repeats
- Use the phrase "Tell me about..."

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To Communicate: Just Having a Conversation

- The more you know, the better it will go
- Take it slow and go with the flow
- Later in the disease:
 - Use props or objects
 - Consider parallel engagement at first: look at the 'thing,' be interested, share it
 - Talk less, wait longer, take turns
 - Cover, don't confront when you aren't getting their words and just enjoy the exchange
 - Use automatic speech and social patterns to start interactions
 - Keep words short and emphasize the visual

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Then Get Going!

Positive Action Starters (PAS)

1. **Help** – Be sure to compliment their skill in this area, then ask for help. *“I could use your help...”*
2. **Try** – Hold up or point to the item you would like to use, possibly sharing in the dislike of the item or task, *“Well, let’s try this.”*
3. **Choice** – Try using visual cues to offer two possibilities or one choice with something else as the other option. *“Coffee or Tea?”*
“This? Or something else?”
4. **Short and Simple** – Give only the first piece of information, *“It’s about time to ...”*
5. **Step by Step** – Only give a small part of the task at first, *“Lean forward....”*

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Give Simple Information:

- **Use Visual Cue (gesture/point) combined with a Verbal Cue:**
 - “Its about time for...”
 - “Let’s go this way...”
 - “Here are your socks...”
- **Don’t ask questions you don’t want to hear the answer to!**
- **Acknowledge the response/reaction to your information**
- **Limit your words and keep it simple**
- **Wait!**

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To Communicate When They're Distressed:

First - Connect

Then - Use Supportive Communication

Finally - Move Together to Something New

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Steps To Communicate and Figure It Out:

1. Connect:

- Visually
- Verbally
- Physically
- Emotionally
- Spiritually

2. How?

- PPA™
- Supportive Communication

3. Supportive Communication:

- Empathy
- Validation
- Exploration
- Acknowledgement

4. Move Forward:

- New words
- New place
- New Activity/Focus

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To Connect When They're *Distressed:*

- **Send Visual Signal of connection:**
 - Look concerned
- **Send a Verbal Signal of connection:**
 - Use the right tone of voice
- **Send a physical signal of connection:**
 - Give a light squeeze or sandwich the hand
 - Offer an open palm on shoulder or back
 - Offer a hug if the person is seeking more contact

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Top Ten Unmet Needs of People Living with Dementia



5 Expressions of Emotional Distress

Angry

irritated – angry – furious

Sad

dissatisfied – sad – hopeless

Lonely

solitary – lonely – abandoned/trapped

Scared

anxious – scared – terrified

Lacking Purpose

disengaged – bored – useless

5 Physical Needs

Intake

Hydration, nourishment, meds

Energy

tired or revved up
(directed inward or outward)

Elimination

Urine, feces, sweat, saliva, tears

Discomfort

4 Fs and 4 Ss

PAIN Free!!!

Physical, emotional, spiritual

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What is Supportive Communication?

- Repeat a few of their words with a question at the end
- Avoid confrontational questions
- Use just a few words
- Go slow
- Use examples
- Fill in the blanks
- Listen, then offer empathy:
“Sounds like...” or “Seems like...” or “Looks like...”

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Tools for Special Services Plans



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Personal Information Sheet:

Preferred name and key life history

Family information

Illnesses or other medical conditions

Medications (drugs, OTC, vitamins, herbs)

- Allergies or histories of bad reactions
- Discourage stopping ACIs if possible (Aricept, Exelon, Reminyl)

Need for glasses, dentures, hearing aid

Amount of help needed for activities

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Personal Information Sheet:

Degree of impairment:

- Memory
- Language
- Understanding
- Hand skills
- Movement
- Judgment
- Impulse control

‘Hot buttons’: things that upset them such as words, actions, responses, etc.

Favorite foods or items that comfort

How do they pain or other unmet needs?

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The GEMS State Model

Positive
Approach
to Care

**GEMS are not discrete stages to which one deteriorates.
Rather, they are states one can move through, moment to moment, or day to day.**

The Positive Approach to Care GEMS® State Model was created to help us see the retained abilities of a person living with dementia (PLWD). An individual's GEMS state indicates retained skill in combination with missing function, so that support and cueing will foster engagement and participation rather than isolation and dysfunction. Recognizing the GEMS state allows us to engage in an appropriate manner and helps the PLWD shine, just as they are, in that moment.



Sapphire

True blue
Healthy brain
Normal aging
Flexible
Adaptable
Optimal cognition
Can provide support for other GEMS states with proper self-care and support
Less peripheral awareness with age



Diamond

Clear – Sharp
Many facets
Lives by habit and routine
Likes familiar, dislikes change
Blames or dismisses errors
Can cut and shine
Scuba vision



Emerald

Green
On the go with purpose
Flawed
Seeks independence or connections
Repeats
Misses details
Travels in time and place
Binocular vision



Amber

Orange
Caught in a moment of time
More curious than cautious
Focused on sensory needs
Lives in the moment
Copies actions, not tasks
Resists dislikes, seeks likes
Can confuse objects



Ruby

Strong red
Retains strength, not skills
Big/strong actions
Has rhythm
Notifies tone of voice
In motion or still
Imitates actions
Monocular vision



Pearl

Hidden in a shell
Ruled by reflexes
Short moments of connection
Mostly immobile
Expresses unmet needs with distress
Reacts to touch
Can recognize familiar and liked
Limited visual regard

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2

What Abilities Do I Observe?



What are the person's observed abilities in this GEMS state?
To use this chart, identify a skill category you have observed, and look down that GEMS column to determine other skills and abilities.

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Their Skills	Sapphire	Diamond	Emerald	Amber	Ruby	Pearl
Vision Changes	Normal vision with peripheral inattention up to 45°	Tunnel vision	Binocular vision, task vision, or social vision	Binocular vision, loss of object recognition	Monocular vision	Brief gazing; may open eyes for sounds of interest
Language-Expressive	A little slower, word-finding problems, pauses	Word-finding problems, misspeaks when stressed, repetitious	Repeats phrases, gets stuck in social chitchat; tone and pitch matter	Repetitive, tends to echo words, variable volume	Babbles, hums, and sings, likes rhythmic sounds, or is silent	Makes sounds, single words in response to strong likes or dislikes
Language-Receptive	Can be challenged in loud, crowded spaces	Slower to understand, may not comprehend all consonants	Misses ¼ of others' spoken words, does better with rhythm	Catches some words or phrases, but out of context	Responds to social chitchat, music, rhythm, tone of voice	Responds to familiar and friendly, calm or excited tones
Dexterity-Hand Skills	Still intact or slightly slower and less skillful	Slower, limited with bilateral, skilled integration	Strong individual actions; completing a sequence of tasks is a bigger challenge	Increased use of hands for sensory input, strong grasp, decreased skilled tool use	Uses whole hand (gross) grasp, holds and carries, decreased grasp release	Strong grasp, limited release; hand may be fisted shut
Body Skills	Intact, slightly slower than when younger	Overall OK, but details or fine motor skills may not be as good	Better with dominant side, some errors may be made with gross motor	More strength than skill, limited safety awareness	Whole body moves as a unit vs. segmented. Can be stable going forward, not backward	Reflexive, much slower movement, typically forward flexed with adducted arms and legs
Awareness of People	Intact, slower to identify others, especially out of context	Some decreased recent recognition; better with older, deeper memories	Recognizes own likes and dislikes with regard to the person and in that moment	In the moment—emphatic likes/dislikes, can't discern old vs. new relationships	Either likes or dislikes, familiar vs. unfamiliar	Responds to familiar/preferred voices, faces, touches, smells
Place Awareness	Intact, may have occasional disorientation	Familiar feels best, may get lost in unfamiliar places	OK unless distressed, then seeks familiar	OK if comfortable <i>here</i> , otherwise will seek elsewhere	Limited environmental awareness—more a pattern of being in motion or still	Responds to comforting experiences and stimuli in the environment
Time Awareness	Lifelong tendencies—late or on time	More focused on the past than present	Lost in episodes or caught in loops	In the moment—it's not about the task or sequence	Immersed in the experience, not the time	Time has much less meaning
Situation Awareness	Intact, may struggle to adapt to circumstances	Old emotions drive new interactions	Has moments of time travel	Has sensory awareness, for in the <i>now</i> , not the situation	Only in moments, less body aware	More internally than externally aware

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Me in the Moment

Preferred Name: _____

Language(primary): _____ Age: _____

Gender Identity: _____

Primary GEMS State: 

Speech: ___ None ___ Accurate ___ Echo ___ Repeats ___ Unintelligible

Comprehension: ___ None ___ 1-word ___ Simple ___ OK

Hearing: ___ Deaf ___ HoH ___ 1:1-OK ___ Group-OK

Activity Preference: ___ Doer ___ Talker ___ Watcher

Pain Present? ___ Physical ___ Emotional ___ Spiritual

Hand Dominance: ___ Right ___ Left ___ Ambidextrous

Personality Trait:

___ Introvert (*private, alone time, SPACE, quiet*) ___ Extrovert (*common areas, talking, close, touching*) ___ Mixed

Family: ___ Married ___ Partnered ___ Widowed ___ Divorced ___ Single

Grew up where (city): _____

Important Family (Name + Relationship): _____

Major Life Events of Note (Positive or Negative): _____

Sensory Preference – Note Likes (*little/lot, same/different, details*) and Dislikes (*speed, variety, types, specifics*):

• Sights:

• Touch/Physical Contact:

• Smells:

• Sounds:

• Movement:

• Tastes:



Productive. Work/Jobs/Valued Roles/Occupation/Military History:

• Current Possibilities:



Leisure. Play/Fun (*Passive Activities and Active Activities*) History:

• Current Possibilities:



Health/Wellness. Self-Care/Physical/Body Fitness/Brain Fitness History:

• Current Possibilities:

Music Preferences:



Rest/Restorative. Spiritual/Wake and Sleep Cycle/Respite/Rejuvenation History:

• Current Possibilities:

What Offers Comfort/Likes? Discomfort/Dislikes? (*animals, plants, flowers, music, people/children/babies, belongings, objects, places/scenery, pictures, art*): _____

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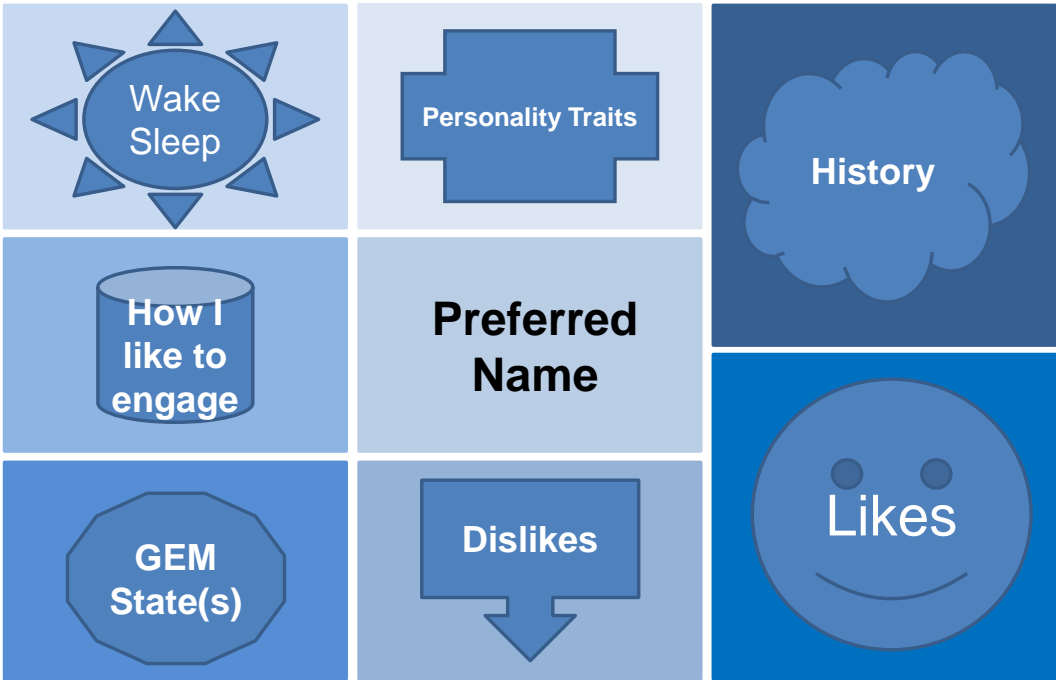
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Visual Info Sharing System: Picture Me

Sharing About Me

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Positions on the Sheet



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Person-Centered Care Planning

Person-centered care is a philosophy of care built around the needs of the individual and contingent upon knowing the unique individual through an inter-personal relationship.*

The National Committee for Quality Assurance (NCQA) is an independent non-profit organization that works to improve health care quality through the administration of evidence-based standards, programs, and accreditation. NCQA provides person-centered care planning resources.

Assessment of Unmet Need (Person may need assistance with)	Person Can (Retained skill/strength)	Interventions (Staff assist with)	Goal (Person will...)	Evaluation (Did goal happen?)

Example:

Bob is irritated when aides dress him. If aides do not recognize this, he becomes angry, then furious to the point of hitting aide to stop	Bob is able to pull up/on his own clothing	Aides will assist by using Hand-under-Hand to fill in skill such as buttoning or when clothing gets caught	Bob is participating in dressing himself with some, but not all, aide assistance	Nurse & aide will re-assess after 2 days to see if Bob is less frustrated with dressing
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* For a review of Person-Centered Care, see: Fazio, S., Pace, D., Flinner, J., Kallmyer, B. (2018).
The Fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, 58 (Suppl. 1), S10-S19.

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