LANGUAGE OF DISTRESS
Behaviors Have Meaning



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Dementia Care and Education Campus

Campus provides a full-spectrum of services and surrounds family members with compassionate support



- The Education Center brings our community together to share best practices in dementia care
- Adult Day Club and Child Center
  - Day Club to provide socialization for participants and provides a break for care partners.
  - An adjacent Child Center provides intergenerational enrichment.
- 12 person Assisted Living Center
- 10 person Hospice Inpatient Home

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Dementia

An umbrella term used to describe a collection of brain diseases and their symptoms, which include: memory loss, impaired judgment, personality changes, and an inability to perform daily activities.

Alzheimer's Disease

Prevalence
60-70% of dementia cases

Characterized by
Amyloid plaques and beta tangles.

Symptoms include
Impairments in memory, language, and visuospatial skills.

Vascular Dementia

Prevalence
10-20% of dementia cases

Characterized by
Disease or injury to the blood vessels leading to the brain.

Symptoms include
Impaired motor skills and judgement.

Frontotemporal Dementia

Prevalence
10% of dementia cases

Characterized by
Deterioration of frontal and temporal lobes of the brain.

Symptoms include
Personality changes and issues with language.

Lewy Body Dementia

Prevalence
5% of dementia cases

Characterized by
Lewy body protein deposits on nerve cells.

Symptoms include
Hallucinations, disordered sleep, impaired thinking and motor skills.

Other Dementias

Prevalence
5% of dementia cases

Dementias related to
- Parkinson's disease
- Huntington's disease
- HIV
- Crutzfeldt-Jakob disease
- Korsakoff syndrome

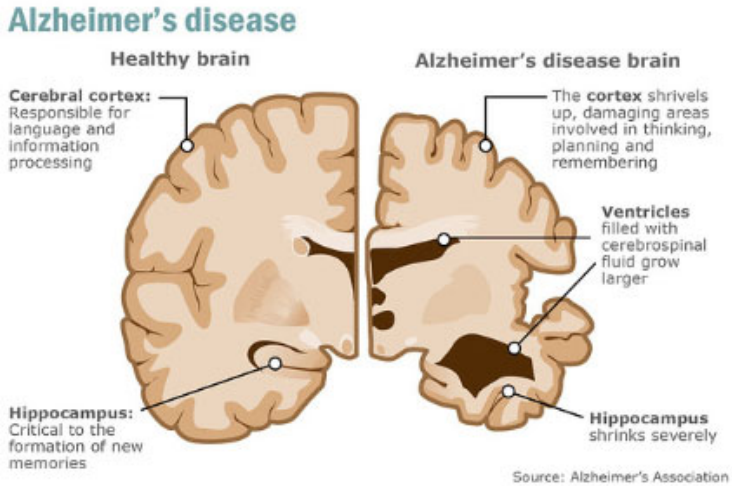
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SIDE VIEW OF BRAIN



Progressive Brain Changes Due to Alzheimer's Disease (AD)

Blue shading indicates the spread of plaques and tangles as dementia progresses.



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~~"Behaviors"~~
Reactions, Expressions

Caution: Labels are sticky and reflect attitudes

What terms are commonly used?

- Difficult
- Manipulative
- Combative
- Agitated
- Wanderer
- Screamer
- Sexually Inappropriate



Be a detective, not a judge!!

-Teepa Snow

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Common Behavioral Expressions

Refrain from using generic terms such as "agitated"

Joyce is agitated
Vs
Joyce is pacing, repeatedly yelling, "I want to go home!"



- **Self-protective** reactions: hitting, escaping, kicking, biting
- **Motor:** pacing, repetitive movements, physical aggression
- **Verbal:** yelling, repetitive vocalization, verbal aggression
- **Emotional**: depression, apathy, anxiety, irritability, anger
- **Resistance** to care (bathing, dressing, medications)
- **Sleep** changes: insomnia, fragmented, flipping, hypersomnia
- **Misperceptions:** Illusions vs. hallucinations; delusions
- **Sexually** Inappropriate behaviors

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Dementia-related behaviors have *meaning*

They serve as expressions of unmet needs

"Language of Distress"

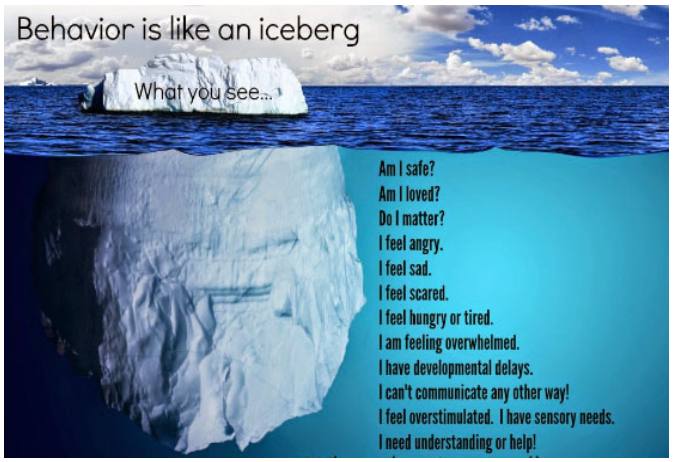
What could be causing/triggering distress?

Physical - pain, hunger/thirst, hot/cold, medical conditions, need to move, fatigue

Emotional - loss of control, fear, anger, frustration, loneliness, boredom, fatigue, anxiety, depressed, grief, lack of meaning or purpose

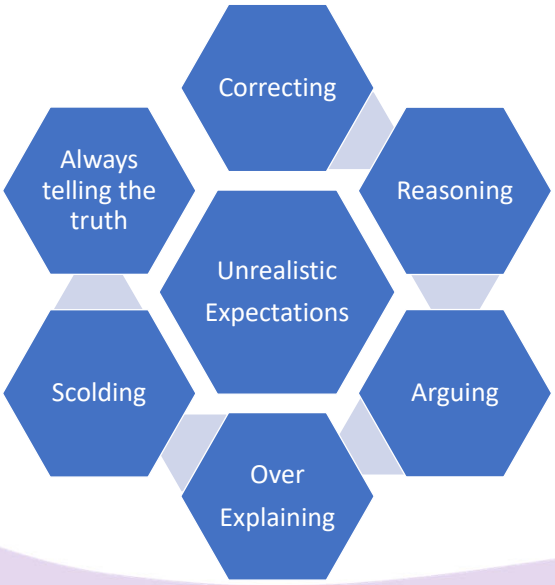
Environmental - any change, under / over-stimulation (consider sensory stimulation and deficits)

What are the underlying factors causing the distress?
Causes are often multifactorial!!



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Inadvertent causes of escalation





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ABC Worksheet
(Antecedent, Behavior, Consequences)

Antecedent / Activator

- What happens right *before the behavior*?
- *When* and *where* does it occur?
- *Who else* is around the person? What are they doing or saying?
- *What* is going on in the environment?
- Any recent changes in physical, mental, or functional status that might indicate a medical cause
  (e.g, pain, constipation, infection)?

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Behavior

What exactly is the person doing?

- Is it dangerous?
- *How often* does it occur? *How long* does it last?
- Does it get worse or better on its own?
- Does anyone or anything make it better or worse?
- Do you have any idea what the person might be trying to communicate?
- Is it *realistic* to expect the person to react any differently given their significant brain changes?

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Consequences

- What does the person do or say afterward?
- Does anyone try to argue, explain, ignore, or confront the person?
- Could the person perceive the voices or body language of others as threatening?
- Does anyone try to connect, comfort, validate and/or redirect the person?

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Rule out Delirium

	Delirium	Dementia
Onset	Sudden (days, weeks)	Insidious (slow, progressive, months/years)
Course	Fluctuating	Gradual decline
Alertness	Hyperalert, lethargic	Usually alert
Hallucinations	Common	Not usually (pending type)
Sleep	Disturbed, no pattern	Disturbed, pattern occurs most nights
Reversibility	Reversible	Not reversible





The '**canary in the coal mine**'

Changes in brain function can signal disorder(s) in other systems in the body.

Ask: **WHEN** did the change(s) in behavior ***begin***?

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A word about *Delirium* – Is the behavior NEW?

Delirium is an acute alteration in mental status *from baseline* occurring over the past days/weeks

- Changes in thinking & concentration
- Difficulty focusing attention
- Illogical thinking and speech
- Excessive daytime drowsiness/sleep or not sleeping at night
- Significant change in behaviors
- Hallucinations or paranoid delusions
- Disoriented

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Common causes of delirium

- Medications
- Infections
- Electrolyte imbalances
- Pain
- Urinary retention or catheterization
- Fecal impaction
- Metabolic changes
- Changes in environment & / or caregivers
- Decreased mobility or sensory input
- Surgery
- Substance withdrawal

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The goal is whole-person comfort

Comfortable people don't exhibit distressed behaviors.

We determine the difference between these faces of persons living with dementia.





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Feelings are "stickier" than thoughts

"I have learned people will forget what you said, people will forget what you did, but people will never forget how you made them feel"

Dr Maya Angelou



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Living in a world of "NO…."

Pause to consider…

What would it feel like?

How might it impact the person?



Aggression. Depression. Resistance. Withdrawal.

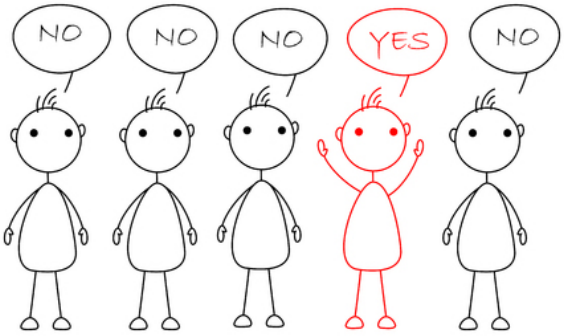
Zeisel, J., Skrajner, M. J., Zeisel, E. B., Wilson, M. N., & Gage, C. (2018). Scripted-IMPROV: Interactive Improvisational Drama With Persons With Dementia—Effects on Engagement, Affect, Depression, and Quality of Life. American Journal of Alzheimer's Disease & Other Dementias®, 33(4), 232-241.

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Create a world that conveys *"YES"*

Validate and affirm using your

- Presence
- Words
- Visual Cues
- Approach
- Environment



Mantra: *Join the Journey*

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Approach Strategies

Start with the "Soft Approach"

- Always introduce yourself
- Smile and warm demeanor
- Get to eye level or below
- Pleasant voice tones/body language
- SLOW DOWN. Talk in short, simple sentences, allow time to process
- Step into their world; "Join the journey" rather than correcting
- Appeal to the emotion, show respect, and let the person know you will keep him/her safe

It can take a brain affected by dementia
20 – 90 seconds to respond to a simple command.

When all else fails: "Thank you so much for telling me"

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Go with the flow and don't say "no"

Be flexible
Do not argue / correct / confront
instead….

Validate, Connect, and Redirect

Validate, Connect and Redirect
by using "yes, and…"

Validate *"Yes, you want to go home…"*
Connect *"…and I want to help you with that"*
Redirect *"How about we get something to drink before we head out? Tell me about your home…."*

Customize pleasurable topics & sensory experiences to redirect the focus of attention.

Make the brain a better offer!

Step into the person's world
Look for the feeling beneath the words and expressions.

What do they need / want to hear?

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Brief Review of Communication Tips



Brain changes lead to communication challenges

- Impaired verbal language
- Slower processing
- Shorter attention span

Adjust your approach to compensate for impairments...

- Say one thing at a time and pause
- *Limit the number* of words
- Use visual cues
- *Slow down* your speech / actions
- Minimize distractions

"Show – Say – Do"

* Try to choose person's best time of day

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Tips for Responding to Emotions

The environment and your presence *significantly* influence the person.



- Calm yourself first
- Minimize distractions
- Create comfortable surroundings
- Be mindful of your:
  - Body language
  - Facial expression
  - Tone of voice
  - Eye contact - place yourself at eye level or below
- Pace yourself with the person's processing abilities
- Offer reassurance & encouragement
- Validate the emotion

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Lead with the human connection….



Be flexible

It's not about the task; it's about the person.

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When the person appears angry or frustrated….

Offer phrases and visual cues to convey…

"This is hard."

"I'm sorry."

"Let's do it together."

And let us never forget to generously use….

"Will you please help me?"

"Thank you so much for telling me."

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About Me®

This information will allow us to personalize this individual's care and honor who they are and what brings them joy. Please do not answer any questions that you feel would violate this person's privacy.

My name is: _____ I prefer to be called: _____
I was born in (city and state): _____
Important people in my life are (include relationship): _____
_____
I like to be remembered for: _____
I like to reminisce about: _____
My work in life includes: _____
My interests, hobbies and talents: _____
_____
Things that bring me peace or solace (prayers, readings, rituals, music, nature): _____
_____
Favorite movies, TV shows, and videos: _____
_____
Music, song or sound preferences: _____
_____
Massage or other forms of touch preferences (neck, hands, feet): _____
_____
Favorite foods and beverages: _____
_____
I like the smell of: _____
My sleeping habits are (waking, napping, things that help me sleep): _____
_____
Things I dislike include (food, situations): _____
_____
Other things I would like you to know about me (routines, quiet time, bath or shower): _____
_____

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Figure 1. The *About Me* form.





- **Learn who they are-** likes and dislikes
- **Give** back their **purpose**- create tasks, ask for help
- **Make it about the person** and not the quality or outcome of the task
- **Sensory engagement-** *GIVE THE BRAIN A BETTER OFFER* (sweets, smells, music, touch, textures, sight, spiritual)
- **Nurture therapy-** mechanical pets and life-like baby dolls
- **Reminisce therapy** and positive statements

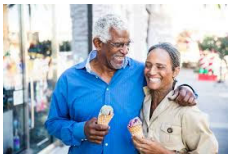
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Sensory engagements

Determine what experiences can bring pleasure

- Taste
- Touch
- Smell
- Sight
- Sound
- Spiritual

















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You can do this!



Become a detective…

Observe the expression of behavior

Look for triggers

Consider….Physical – Emotional – Environmental

What might bring comfort?

Trial ideas and observe responses

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"Cure sometimes, treat often, comfort always."



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What is one thing you learned today?



Thank you!

To learn more, view our educational videos
www.hov.org/dementia

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We are devoted to helping people *live well with dementia.*



Our Phoenix campus is the first of its kind in the United States!

A program of not-for-profit
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PLUS
- Adult Day Club
- Assisted Living
- Inpatient Care
- Intergenerational Preschool

Our campus offers education for every *stage* and *type* of dementia.

No Cost…

- Music Therapy
- Exercise Classes
- Skills Workshops
- Support Groups
- Mindfulness Training
- Support at Home

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We're available 24/7

(602) 767-8300

Thank you for coming!

DementiaCampus.org

Follow us on Facebook, Instagram and dementiacampus.org for tips, classes and more!

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