

NON-MEDICATION STRATEGIES FOR DEMENTIA BEHAVIORS

NOVEMBER 24, 2020

Dr. Aida Wen

University of Hawaii

John A Burns School of Medicine

Department of Geriatric Medicine

Sponsored by



CATHOLIC CHARITIES
HAWAII
CIRCLE OF CARE FOR DEMENTIA

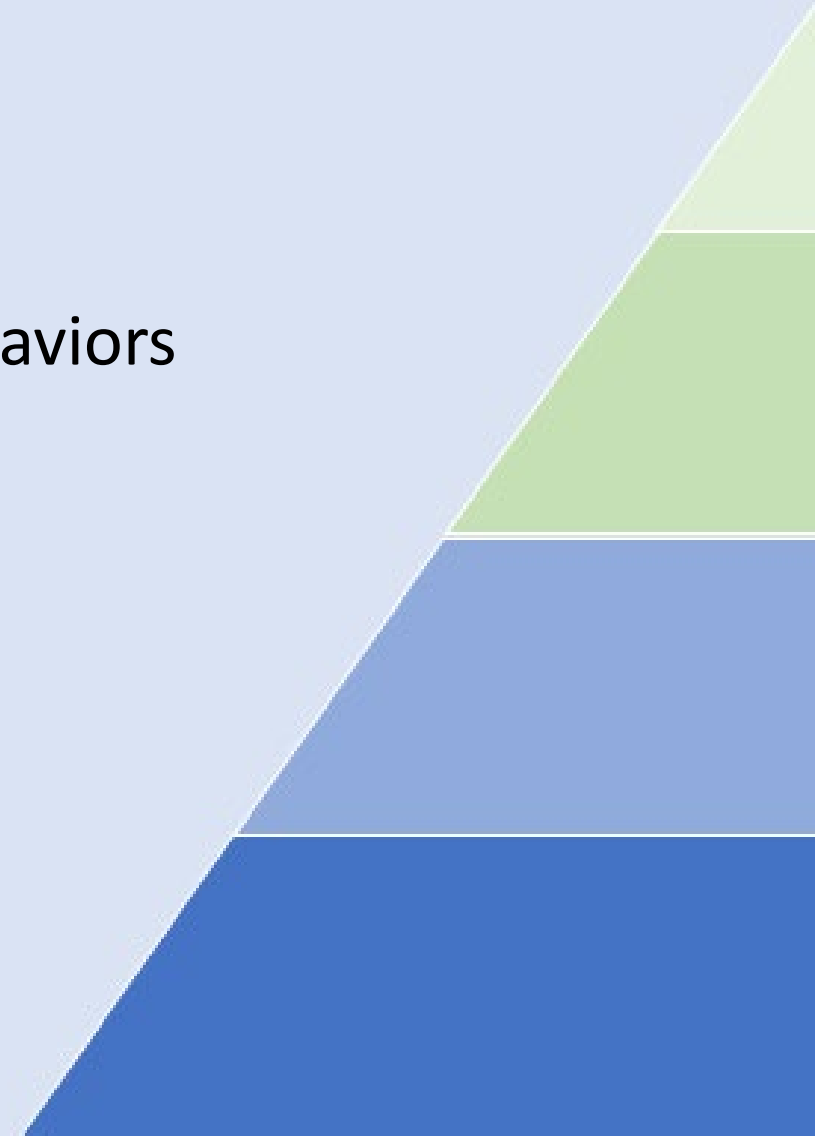


Pacific Islands Geriatric Education Center
Department of Geriatric Medicine John A. Burns
School of Medicine, University of Hawaii

Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.

What we will cover:

- Dementia Basics
- Common Scenarios
- Practical Approaches for Managing Dementia Behaviors

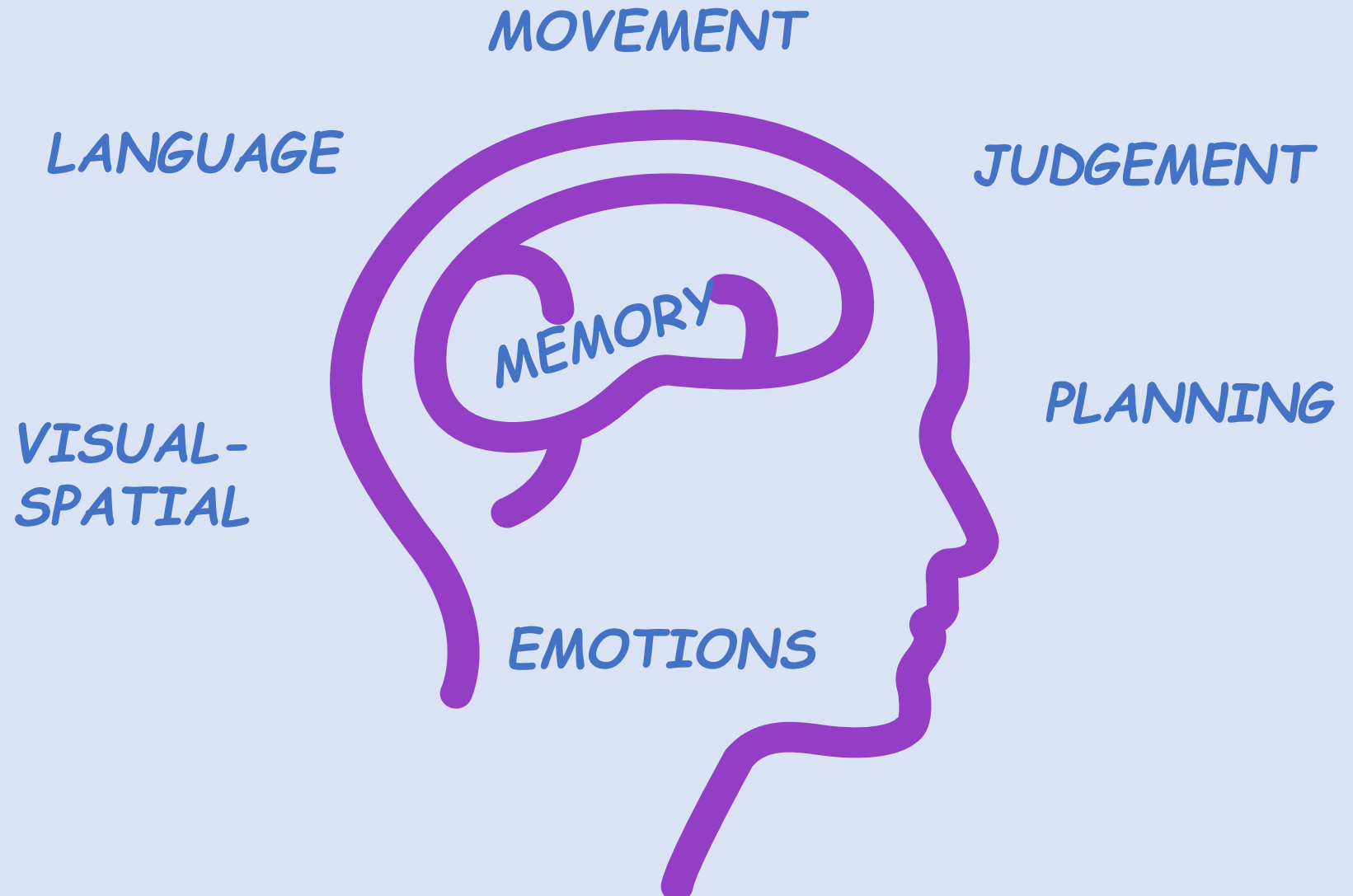


Dementia Basics



DEMENTIA IS NOT just memory problems

It often involves
memory and
OTHER brain
functions as well



DEMENTIA causes problems with FUNCTION



Trouble with complex tasks
Trouble with everyday tasks

Frustration

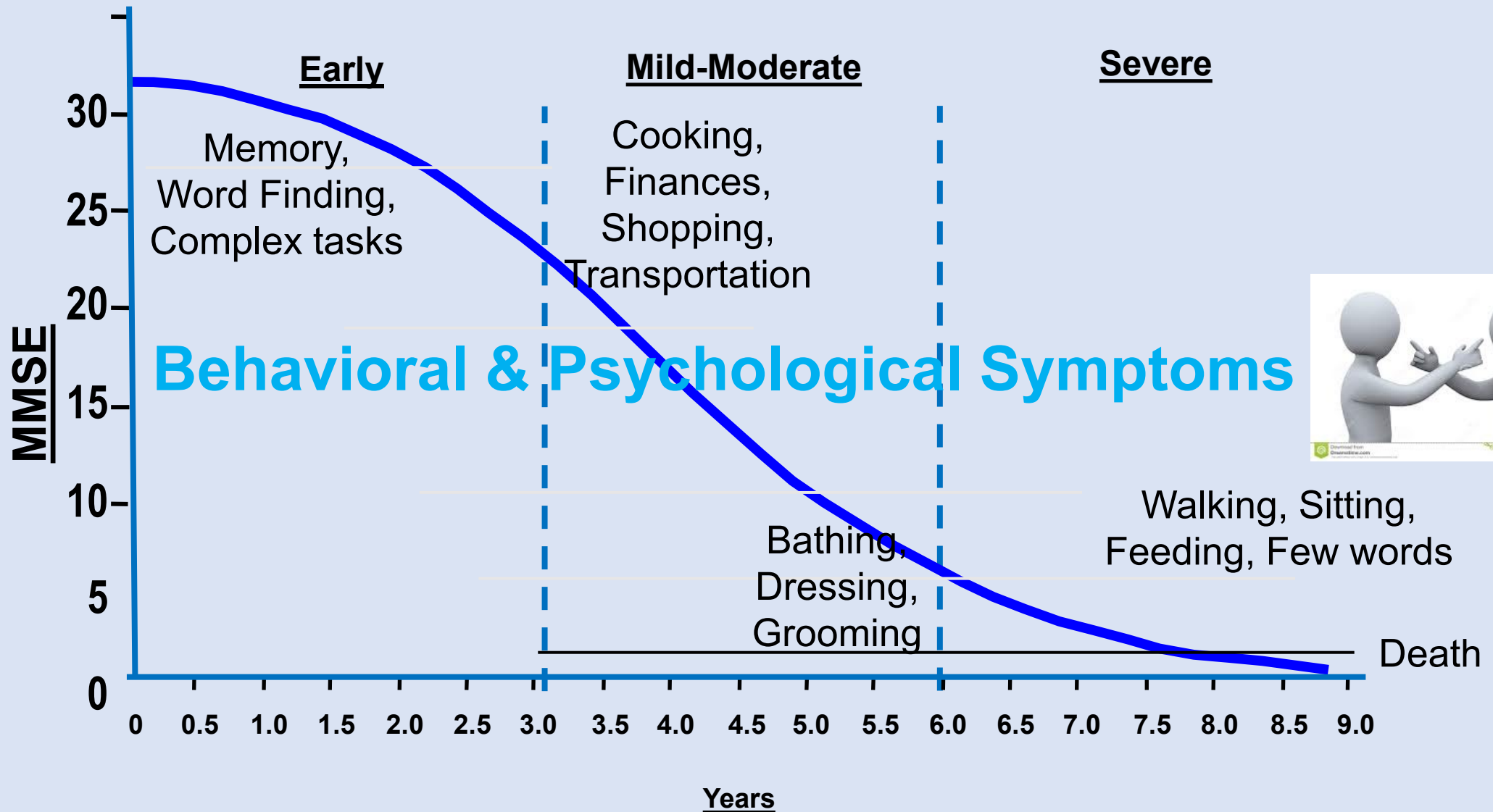
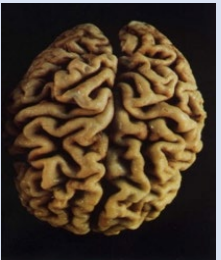
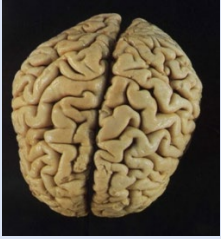
DEMENTIA causes problems with BEHAVIORS



Difficulty with
Behaviors and
Relationships

Misunderstandings

Dementia Progression

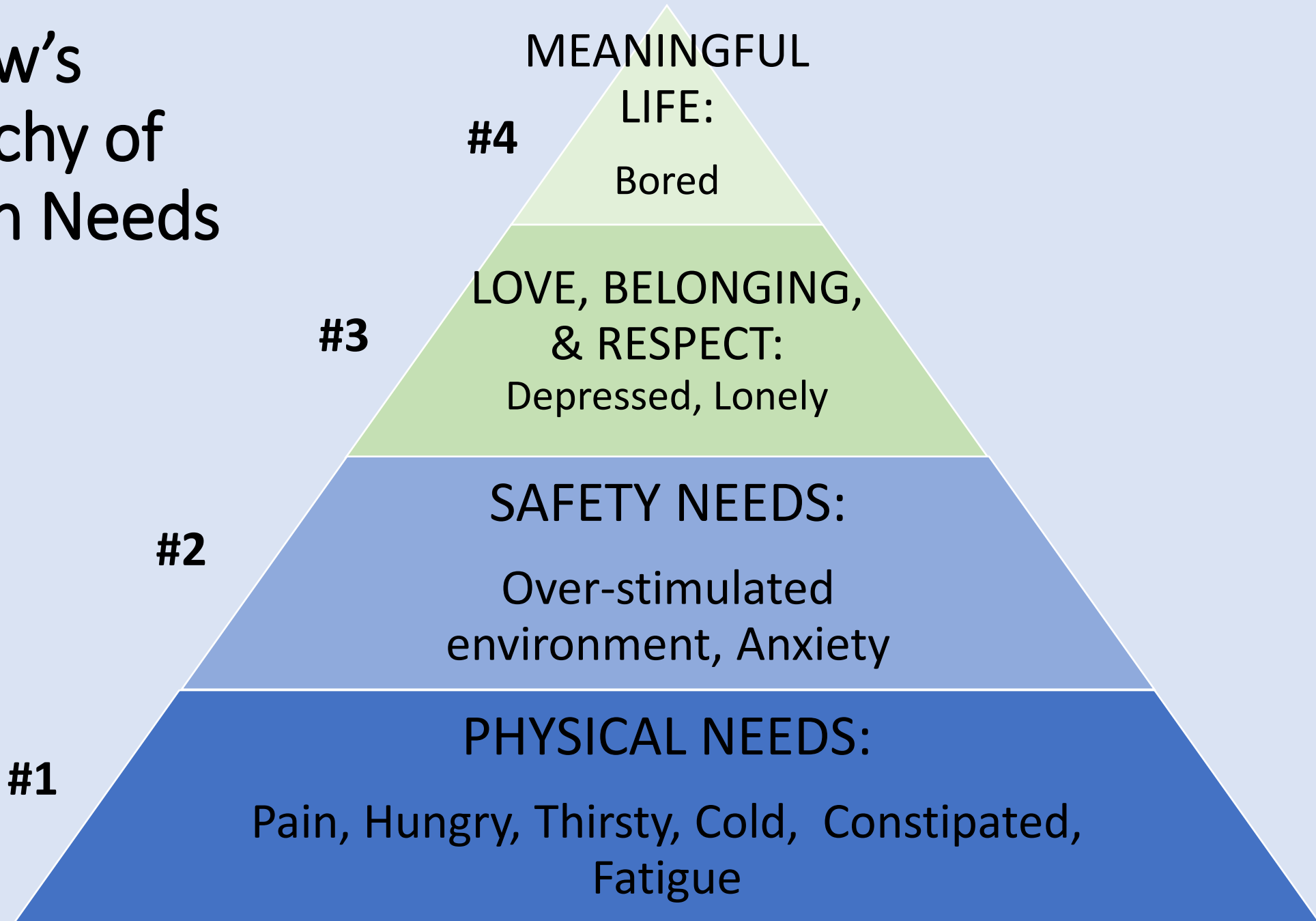


Behaviors = Communication of Unmet Needs



- They can't find the words, and unable to cope with challenges.
- You have to “read their mind” or
- Be a Detective— Get “in his shoes” and Look for his unmet needs:
 - Think about the Hierarchy of Human Needs
 - Pay attention to the details of the situation:
 - Ask: Who, What, When, Where, Why, How?

Maslow's Hierarchy of Human Needs



NEED #1: Consider and Anticipate Basic Physical Needs

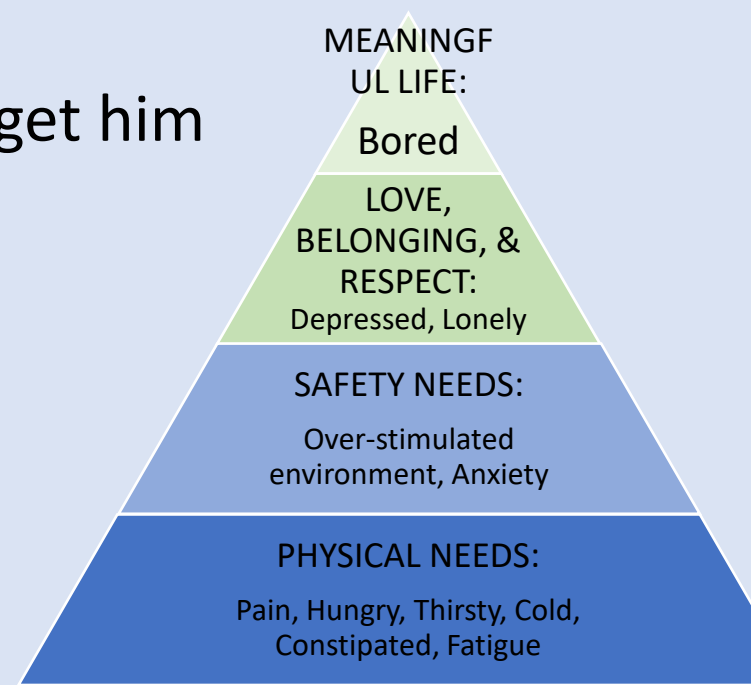


- EXAMPLES: Pain, Hungry, Thirsty, Cold, Constipation, Tired

Challenging Scenario 1

Resistive to Personal Care

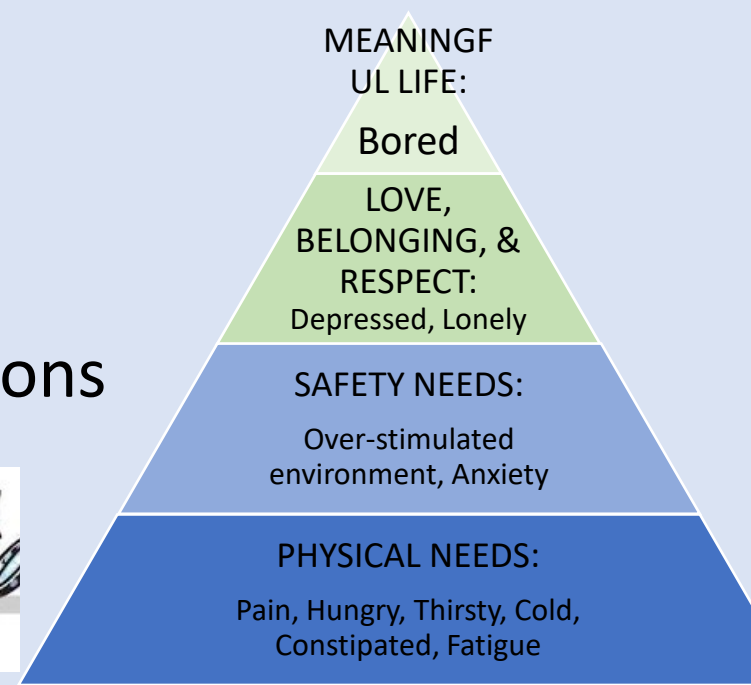
- John hasn't been the same since he slipped from his chair 2 days ago. There were no obvious injuries, and he was able to walk after that. However, since then, he has been more irritable, refusing to get out of bed, and pushing you away when you try to help him. He yells at you to leave him alone.
- When does this happen? 2 days ago, when you try to get him out of bed
- What is going on? PAIN
- What should we do? TYLENOL



Challenging Scenario 2

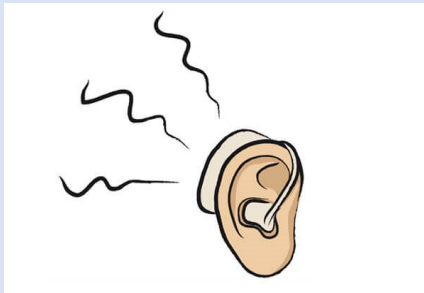
Screaming

- Anne has screaming episodes every three days or so. Sometimes this can go on for hours, and she is inconsolable. This is usually relieved after having a large bowel movement.
- When does this happen? Every 3 days
- What is going on? Constipation
- What should we do? Fiber, fluids, Bowel medications



NEED #2: Safety

Maximize
Sensory Input



Labels, Clocks,
and Calendars



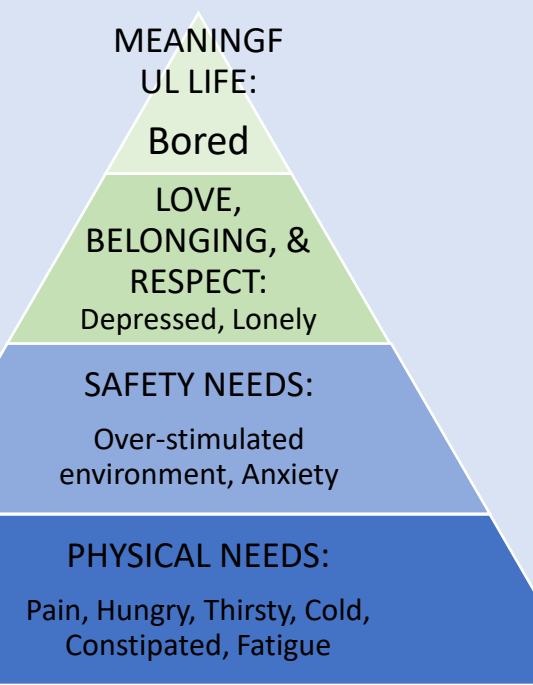
A Less Frustrating Environment is a “Safer” Environment

Challenging Scenario 5

Rampage!

It is 10 am, and Grandma is on a rampage! She started emptying all her dressers, looking for something, and now clothes are all over the room. Now she doesn't even remember what she was looking for! But now she is mad at you because you stole her glasses, and you are always touching her stuff and misplacing things.

- When did this happen? 10 am
- What is going on? Looking for something. Frustrated.
- What should we do? Make her environment less frustrating. Simplify and label dresser.



NEED #2: Safety



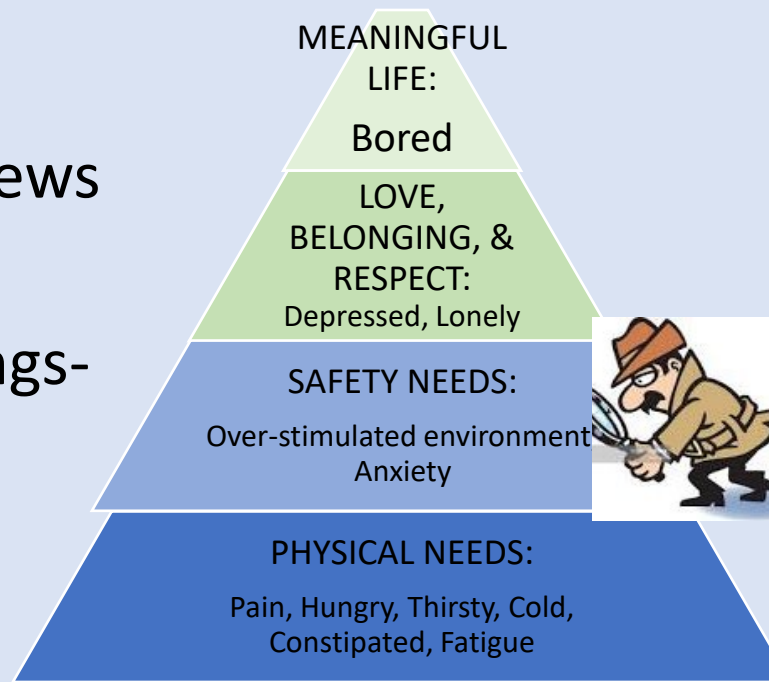
Calm, Comfortable & Safe Environments

Challenging Scenario 3

Repetitive Calling Out

Mom is watching the afternoon news (about the pandemic, wildfires, and protests) and begins banging on the table calling out for you every 5 minutes. When you ask her what she wants, she can't tell you. She just wants you to sit down with her.

- When does this happen? Afternoon, watching the news
- What is going on? Anxiety
- What should we do? Stop the TV. Address her feelings- Provide reassurance.

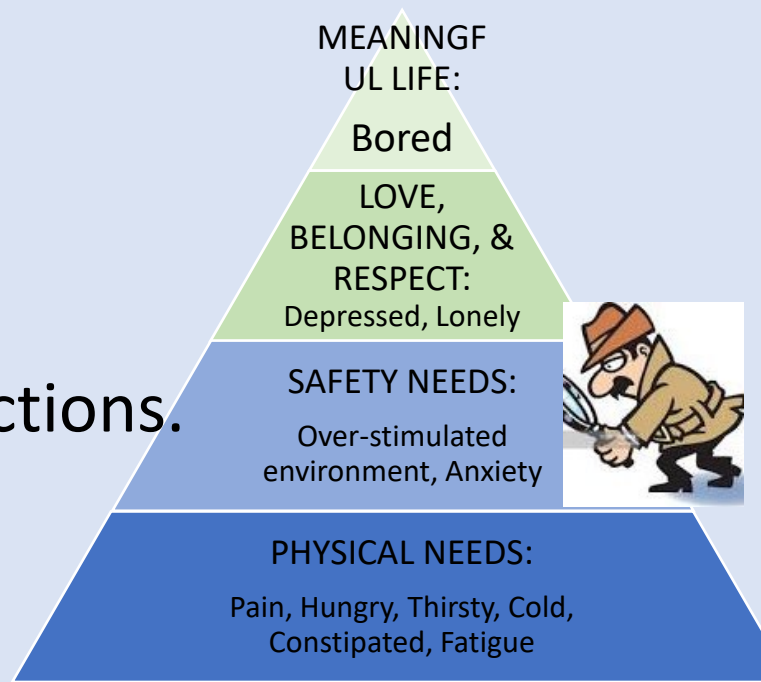


Challenging Scenario 4

Overwhelmed

Your sister and family with 3 kids have flown into town to visit mom and dad. The big family reunion began very joyfully, but after lunch, dad became very grouchy, went into the bedroom and refused to come out for dinner. Your sister is upset, but dad waves them away.

- When? Afternoon, after noisy reunion.
- What is going on? Overstimulation
- What should we do? Provide more quiet interactions.



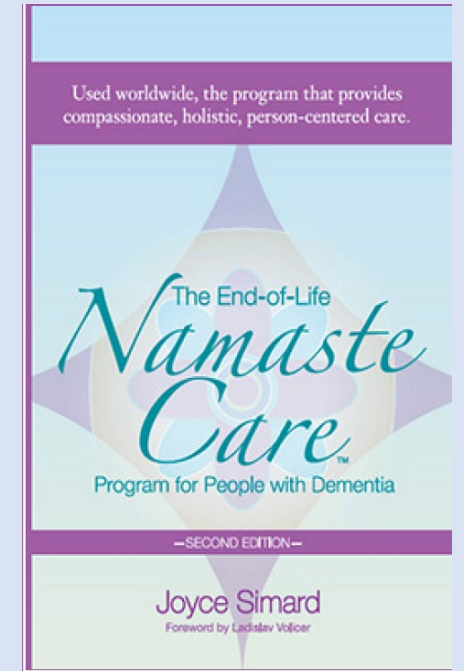
Namaste Care

Hale Nani Namaste Room



“To Honor the Spirit Within”

A Safe and Quiet environment with soothing sounds, gentle touch, and gentle sensory stimulation



Namaste Care

- Placed in a comfortable lounge chair
- Greeted with gentle touch
- A quilt or blanket is tucked around them
- Extra pillows & towels for positioning
- Attention given during Personal care (wash face, shaving, brush hair)
- Videos, nature, music
- Individual reminiscence
- Foot washing and lotion
- Range of motion
- Family visits



Namaste Care



GENTLE ADL CARE
RANGE OF MOTION

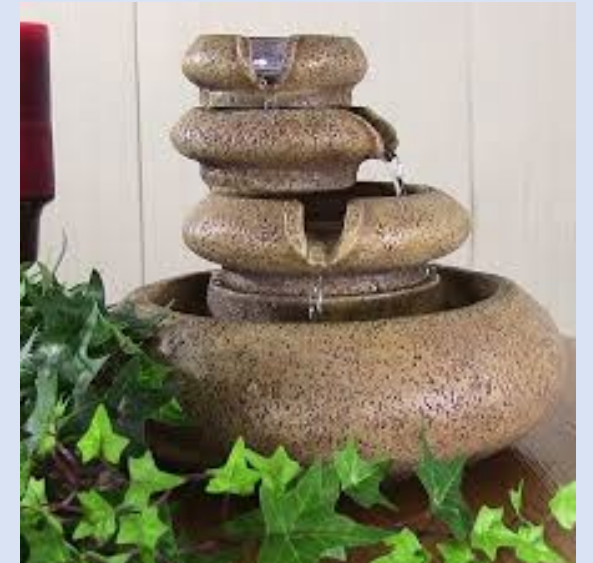




Soft touch



Soothing Sounds





TASTE



NATURE VIDEOS



MASSAGE



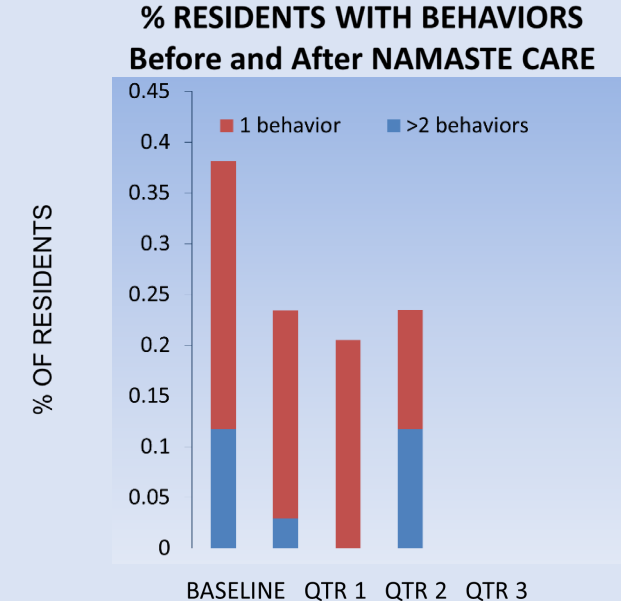
Behavioral Symptoms Among Patients Before and After Implementation of a Specialized Advanced Dementia Care Program in a Nursing Home.

Aida Wen MD; Christina Bell MD; Kamal Masaki MD; John J Megara NHA MBA; Ladislav Volicer MD PhD.

N=45, >89 years old

Looked at behaviors 3 months prior, then followed for 9 months after enrollment

- Significant reduction in % of residents with behaviors
- Significant reduction of total behavior severity scores
 - Especially with rejection of care
- Trend towards reduced use of psychoactive medication use



	BEHAVIOR SCORES		p-value
	Before and After NAMASTE CARE Mean Score (BASELINE) n=34	Mean Score (QTR 1) n=34	
PHYSICAL BEHAVIORS	.06	0	0.160
VERBAL BEHAVIORS	.06	.03	0.325
OTHER BEHAVIORS	.35	.21	0.058
REJECTION OF CARE	.26	.06	0.006
OVERALL BEHAVIOR	.74	.29	0.007



Behavioral Symptoms Among Patients Before and After Implementation of a Specialized Advanced Dementia Care Program in a Nursing Home.

Aida Wen MD; Christina Bell MD; Kamal Masaki MD; John J Megara NHA MBA; Ladislav Volicer MD PhD.

- Residents: decreased agitation, more responsive, skin better
- Staff satisfaction: This works!
- Family satisfaction: Her face was glowing, smiling. I learned how to use gentle touch. I do not leave feeling depressed.

More Evidence for Sensory Stimulation

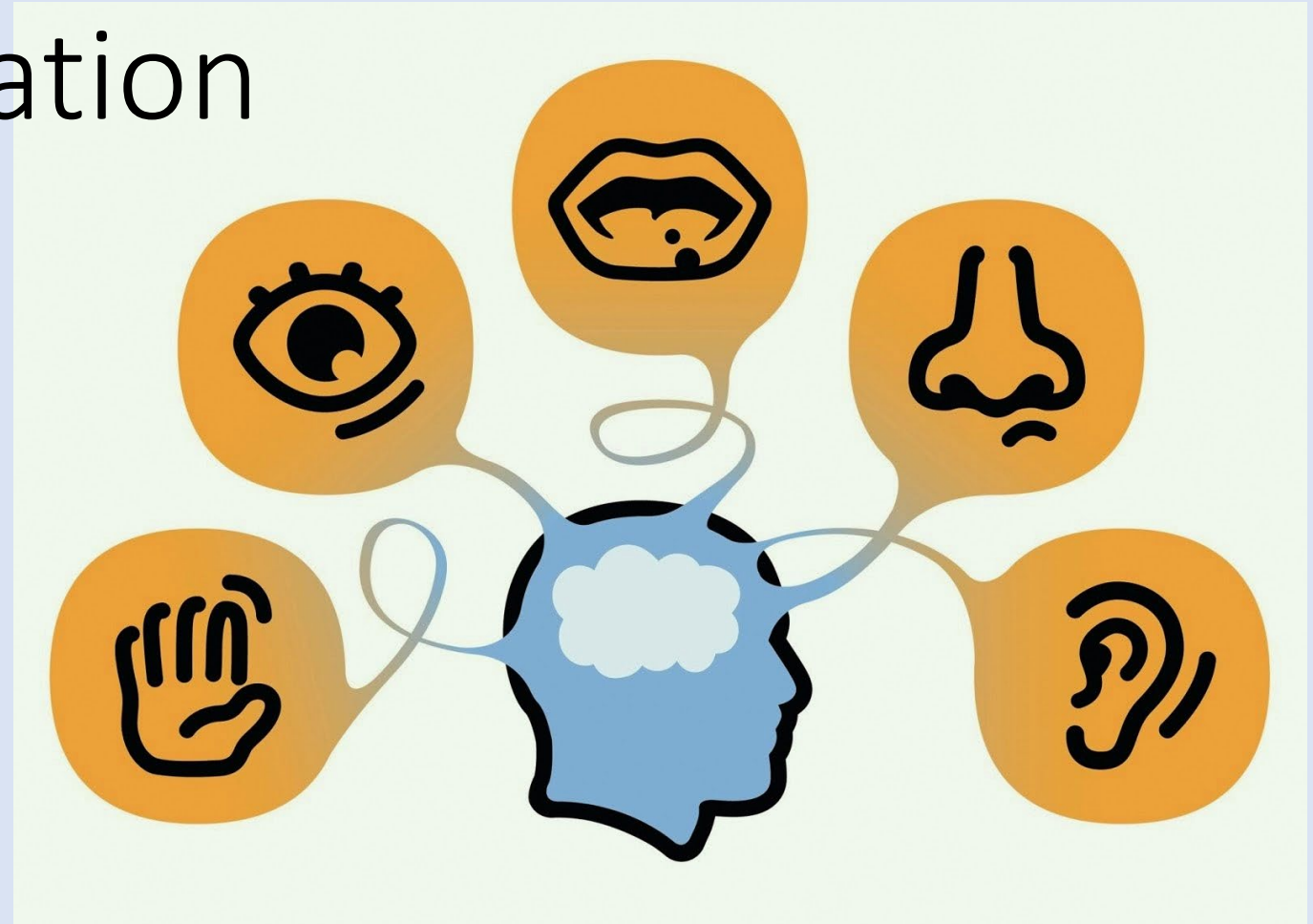
Because primary studies on
non-drug interventions have
limited sample sizes

Evidence is based on
Systematic Reviews
(selects out high quality
studies and combines data
from many smaller studies)

Livingston 2014

Abraha 2016

Dyer 2017



Snoezelen Multisensory Environment



TOUCH



Visual



Especially for Later Stages of Dementia

Snoezelen Multisensory Stimulation Therapy



Abraha, 2016

Systematic review of systematic reviews of nonpharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series

REVIEW OF 3 large Randomized Controlled Trials of Snoezelen:

- 1st study: (n=50) No significant effects
- 2nd study: (n=136) Significant mean differences on scores for Enjoyment, Bored/Inactive outcomes.
- 3rd Study: (n=125) showed significant mean differences on scores of being more happy and content than the control group

Less Bored or Inactive

MD=-0.56;
95% CI (-1.11 to -0.01);
z=1.99, p=0.05).

More Enjoyment

MD=-0.74;
95% CI (-1.29 to -0.19);
z=2.62, p=0.01)

More Happy and Content

MD=-0.84;
95% CI (-1.39 to -0.29);
z=2.98, p=0.003).

Abraha, 2016

Systematic review of systematic reviews of nonpharmacological interventions to treat behavioural disturbances in older patients with dementia. The SENATOR-OnTop series

- Not enough evidence for other types of Sensory Simulation
 - Shiatsu and Acupressure – one RCT (n=133). agitation, aggression and physically non-aggressive behaviors all declined significantly.
 - Aromatherapy- Mixed results with 1 study favorable (n=72), and 1 study with no effect (n=63). *
 - Massage Therapy- multiple reviews found improvement in mean agitation scores *
 - Sensory Garden- one study had non-statistically significant decline in behaviors. Among 2 RCTs, one significant, one no difference.

* Limitations in quality, size, design, and selection bias



Livingston, 2014

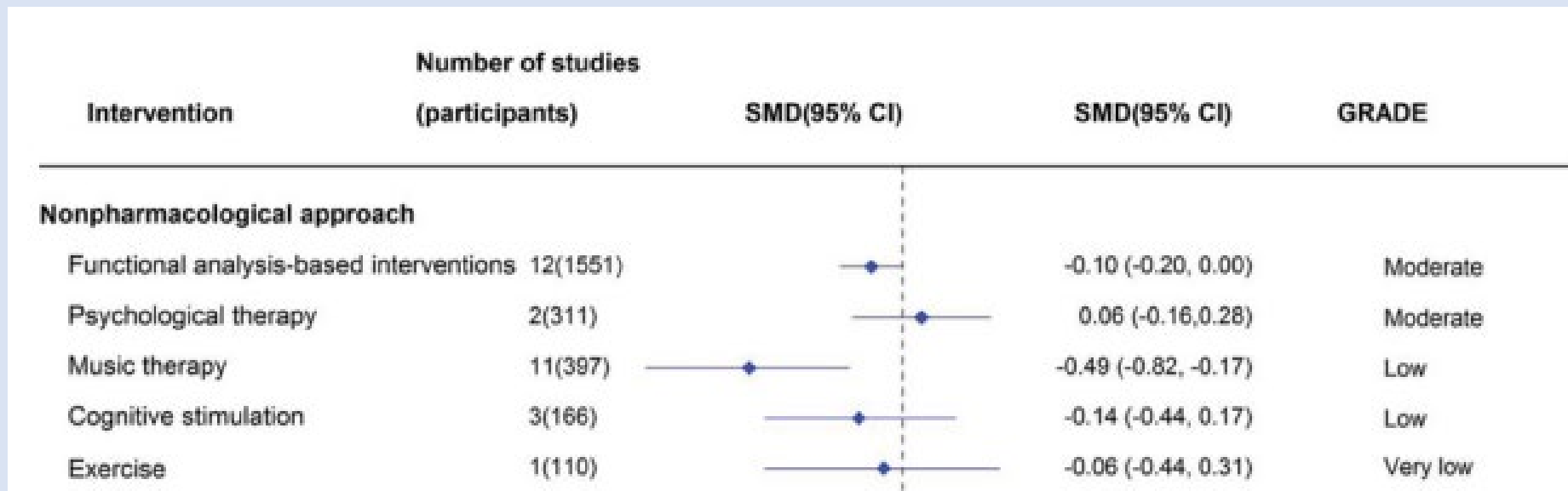


Systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioral interventions for managing agitation in older adults with dementia

- Activities -0.8 to -0.6
- Music Therapy -0.8 to -0.5
- **Sensory Interventions -1.3 to -0.6**
- Person-centered Care and Communication Skills -1.8 to -0.3

Evidence for Music Therapy

- **Livingston, 2014** SES -0.8 to -0.5
- **Ueda, 2013** Music therapy was effective in reducing agitation (SMD, -0.49; 95% CI -0.82 to -0.17; $p=0.003$), and anxiety (SMD, -0.64; 95% CI -1.05 to -0.24; $p=0.002$)
- **Dyer, 2017** SMD -0.49 (-0.82 to -0.17)



←
intervention effective

Compared to other non-drug interventions for Dementia Behaviors, Music Therapy has the most evidence for effectiveness



- Typically, music therapy sessions were twice a week x 6 weeks improved the mean level of agitation symptoms
- Most studies had music therapy 2-3x per week
- Followed a specific protocol:
 - Ex: Warm up of a well-known song, listening to, music, then joining in with music

**Decreased behaviors, depression
and anxiety symptoms**

iPod Music & Memory Program

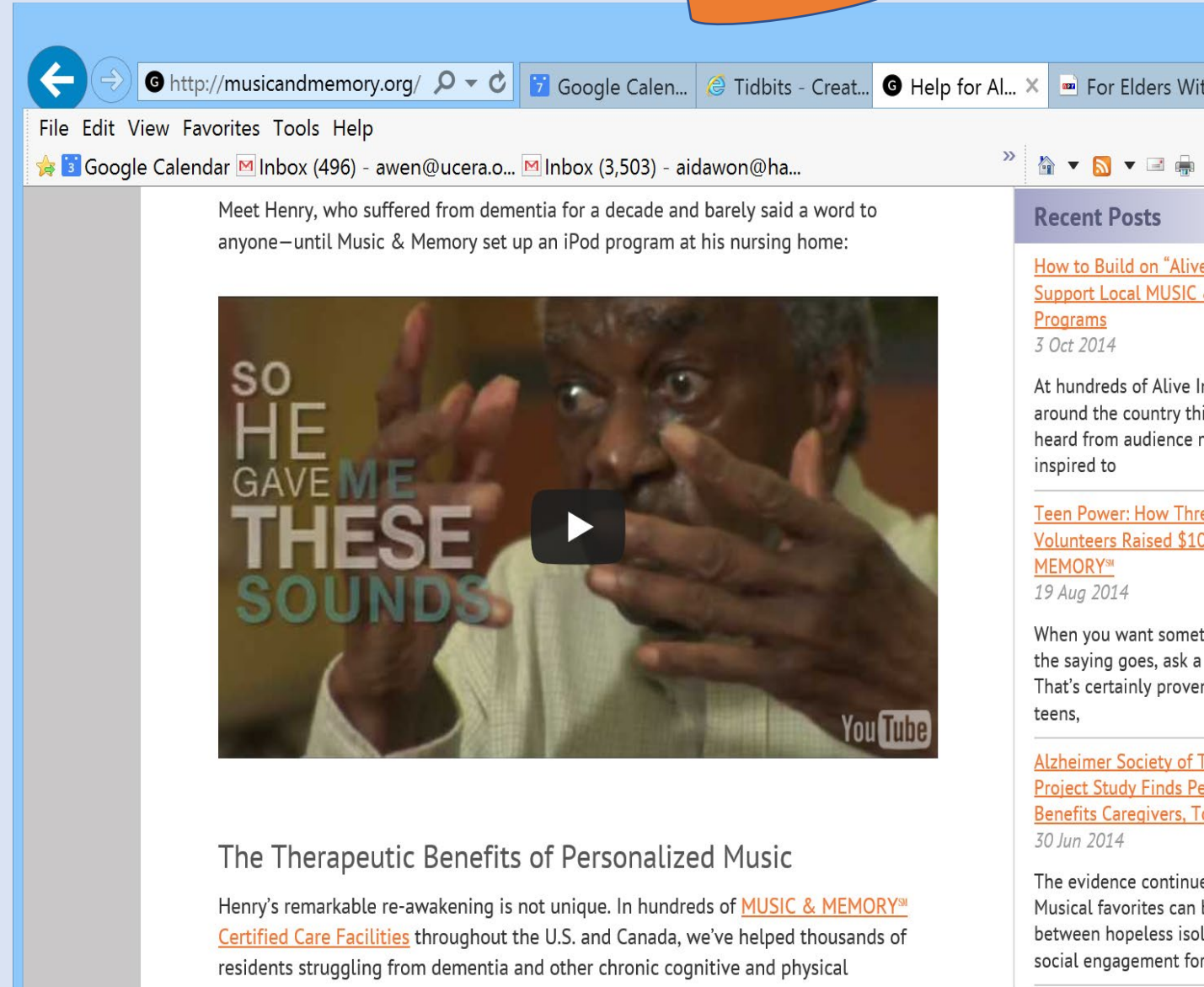
INTERACTIVE!

Widely publicized

- Alzheimer's Association, NPR, NYT, CNN, etc
- "Alive Inside" Documentary (Dan Cohen)

Personalized music playlists
Musical favorites tap deep
memories bring residents and
clients back to life
Best used during Transitions.

Musicandmemory.org/



The screenshot shows a web browser window with the URL <http://musicandmemory.org/>. The page features a video player with a play button and the text "SO HE GAVE ME THESE SOUNDS". Below the video, the text reads: "Meet Henry, who suffered from dementia for a decade and barely said a word to anyone—until Music & Memory set up an iPod program at his nursing home:". To the right, there is a "Recent Posts" section with several article titles and dates, including "How to Build on 'Alive Inside'", "Teen Power: How Thirteen Volunteers Raised \$10,000 for MUSIC & MEMORY", and "Alzheimer Society of Toronto Project Study Finds Potential Benefits Caregivers, Too".

File Edit View Favorites Tools Help

Google Calendar Inbox (496) - awen@ucera.o... Inbox (3,503) - aidawon@ha...

Meet Henry, who suffered from dementia for a decade and barely said a word to anyone—until Music & Memory set up an iPod program at his nursing home:

SO HE GAVE ME THESE SOUNDS

YouTube

The Therapeutic Benefits of Personalized Music

Henry's remarkable re-awakening is not unique. In hundreds of [MUSIC & MEMORYSM Certified Care Facilities](#) throughout the U.S. and Canada, we've helped thousands of residents struggling from dementia and other chronic cognitive and physical

Recent Posts

[How to Build on "Alive Inside": Support Local MUSIC & MEMORY Programs](#)
3 Oct 2014

At hundreds of Alive Inside programs around the country this fall, we heard from audience members inspired to

[Teen Power: How Thirteen Volunteers Raised \\$10,000 for MUSIC & MEMORYSM](#)
19 Aug 2014

When you want something to say, the saying goes, ask a teenager. That's certainly proven for teens,

[Alzheimer Society of Toronto Project Study Finds Potential Benefits Caregivers, Too](#)
30 Jun 2014

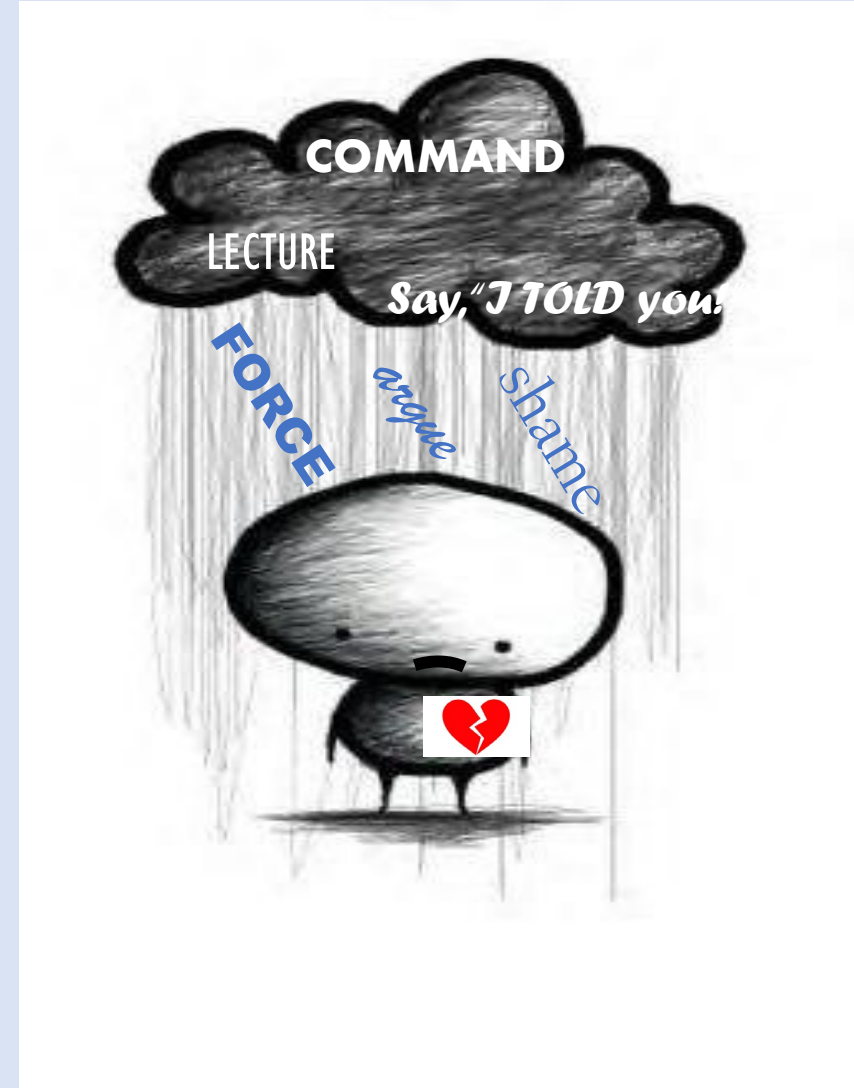
The evidence continues to show that musical favorites can help bridge the gap between hopeless isolation and social engagement for

NEED #3: Love, Belonging, and Respect

Arguing does not help

Always treat with
honor

“Listening” to their
feelings does help

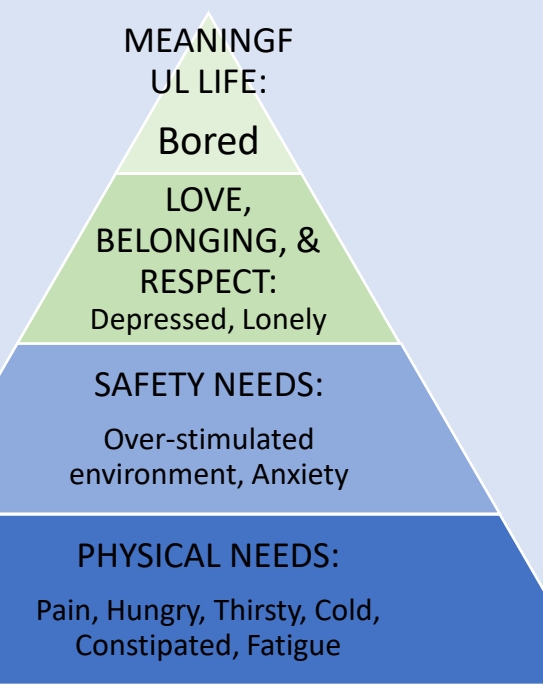


Challenging Scenario 5

I want to go home!

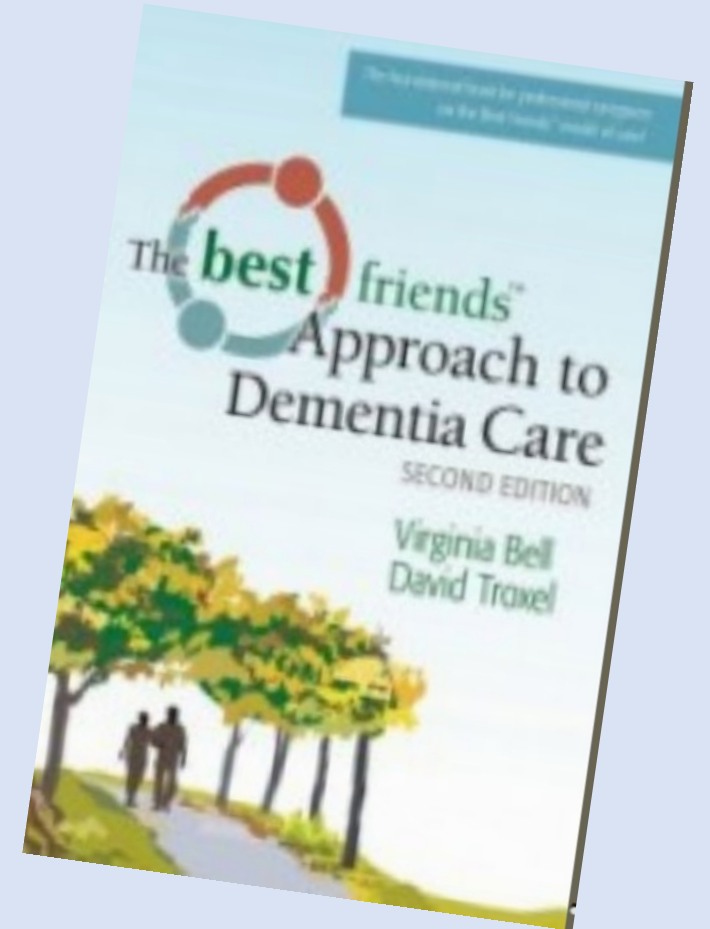
Dad moved in 2 weeks ago, and has been restless every evening around 4pm, trying to leave the house. When you tell him this is his new home. Mom died, and the house was sold. He gets mad at you and says “you know nothing!” and insists this is NOT his home!

- When did this happen? 4 pm
- What is going on? Doesn't belong,
- What should we do? Have familiar items, become “become best friends”, Redirection



A “Best Friends” Approach works Wonders

- Validate Feelings
- Reassure
- Listen
- Show Affection
- Ask for Permission
- Encourage
- Give Compliments
- Are equals- Help each other “save face”



Being Present= Focusing on the Relationship

Enjoy each other...

- Know each other - Reminisce
- Do fun things together
- Enjoy simple things together
- Celebrate special occasions together
- Tell funny stories often
- Laugh together

It's not about the "Task"...
It's more about "BEING"
with the person.

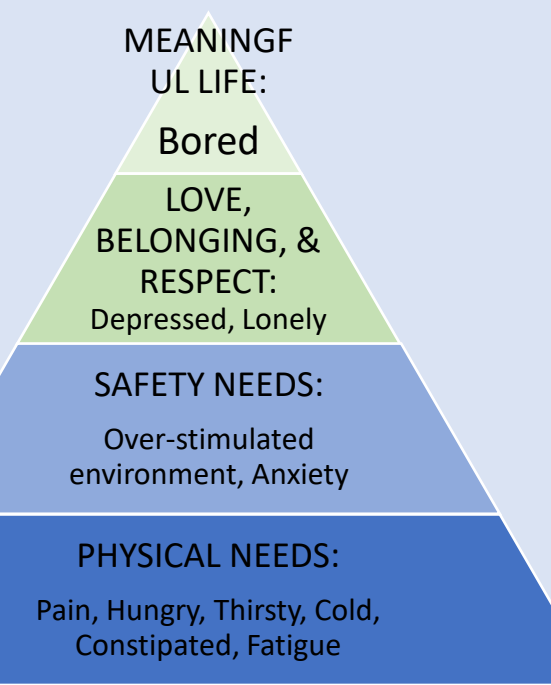


Challenging Scenario 6

Time for your bath

It's 6pm. You and your Aunty finished dinner, and she has food spills on her shirt. You tell Aunty that she is a mess, and she should probably have a bath. You tell her to head to the bathroom, and you'll meet her there to help her. She is indignant and refuses. She said she doesn't need a bath, and she doesn't need your help.

- When did this happen? 6 pm after dinner.
- What is going on? Feels disrespected. She doesn't know what to do.
- What should we do? Help her save face. Simple steps.



Simplify, Demonstrate & Take More Time

- Give basic information (no verbal diarrhea)
- Give SIMPLE single step directions
- If no response, WAIT (silently count to 10) before asking again
- Ask them to HELP you.
- SHOW and do things TOGETHER.
- If responding, give lots of ENCOURAGEMENT
 - Yes!, Good Job, Thank you,
 - Smile, Nod, Hug, Stroke

Scenario: It's time for your Bath!



Preparation

- Familiar person of the same gender
- Gather everything ahead of time (towels, mat, washcloth, comb, etc)
- Make sure room is warm enough and water is the right temperature
- Have a shower bench
- Use a hand-held shower (or scoop/cup)
- Bathing 2-3x per week is usually plenty (just clean “private” areas every day with towel/sponge)
- Consider sponge bath
- Washing hair in the sink may be easier
- Get their favorite music ready

Invitation

- Establish connection before making request.
- Try different words. “spa”, “freshen up”
- Suggest a reward

Strategies

- Tell them what is happening one step at a time
- Provide **Visual, Verbal and Tactile** cues
- **Give the person choices**
- Ask them to check the water to see if its is warm enough
- Give them a washcloth even if they can't help
- **Allow them to do as much as possible**
- Lay a towel over his lap to **protect privacy**, and use washcloth to clean under the towel
- Start at the feet, slowly move up
- Play soft music to relax them
- **Distract** by talking, singing, asking them to help hold things for you
- **Give Encouragement:** visual, verbal, tactile
 - Nod yes, big smile, “thank you!”, high five or shaka

Livingston, 2014



Systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioral interventions for managing agitation in older adults with dementia

Interventions Categories with evidence of efficacy (Standard Effect Size, SES)

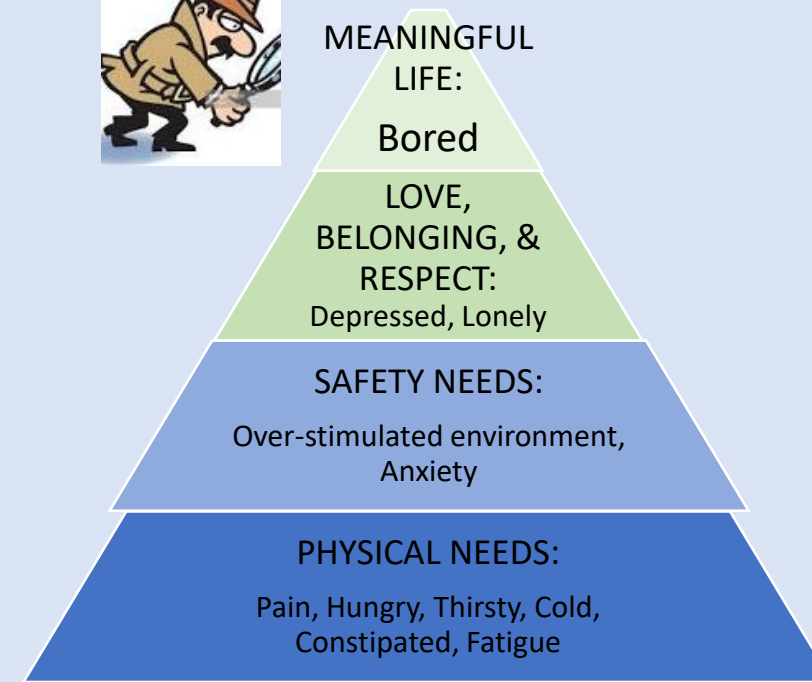
- Activities -0.8 to -0.6
- Music Therapy -0.8 to -0.5
- Sensory Interventions -1.3 to -0.6
- Person-centered Care and Communication Skills -1.8 to -0.3

Challenging Scenario 7

Restless wandering

Harold has been rolling himself in his wheelchair up and down the hallway for hours at a time. He does this every day. Sometimes he tries to stand up and reach something, rummage through closets, or get up and walk, or toilet himself on his own. You are exhausted because you cannot keep your eye on him for every waking minute.

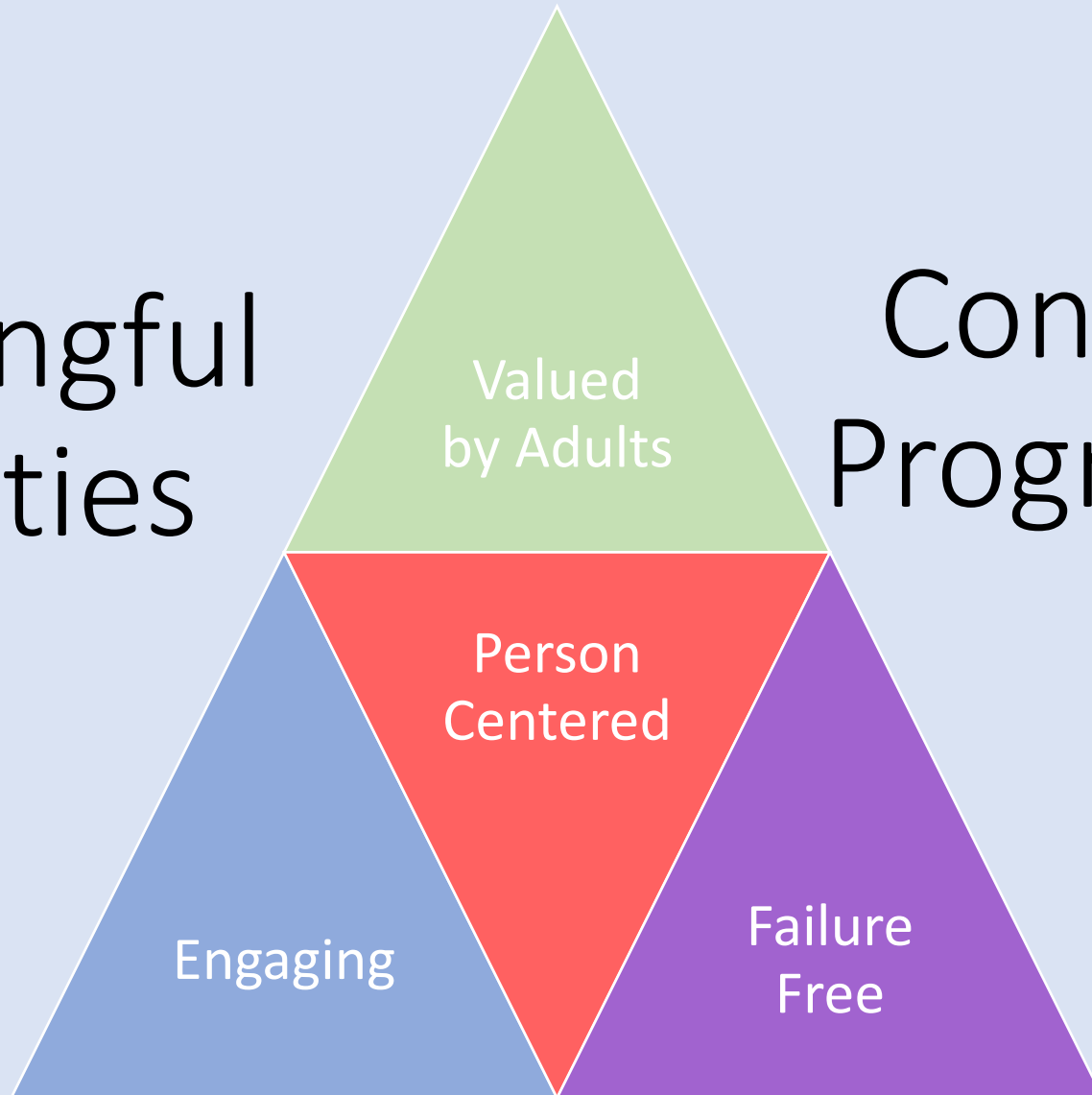
- When? All day
- What is going on? Looking for something to do.
- What should we do? Keep him busy with meaningful activities.



NEED #4: MEANINGFUL LIFE

Meaningful
Activities

Continuous
Programming



Work Activities



Kahala Nui Memory Support Unit



Hale Kuike

Work activities (being productive and helpful)

Ex: gardening, cooking, cleaning, laundry, woodwork, fundraising, etc

Self-Care



Self-care

Ex: “independence”, ADLs, exercise, Get hair done

Leisure Activities



Hale Kuike



Maunalani

Leisure

Ex: flower arranging, creative artwork

Leisure Activities



Leisure

Ex: flower arranging, visiting, playing games, watching musical/
movie

Leisure Activities



Leisure
Ex: playing games, movies



Kahala Nui

Relaxing Activities



Relaxing

Ex: napping, rocking, holding hands, massage, watching fish, petting dog

Reminiscing

Maunalani



Use photos in plastic sleeves or frames that can be easily sanitized



Special Occasions and Events



- Birthdays
- Veteran's Day
- Christmas
- New Years
- Valentine's Day
- Easter
- Mother's Day
- May Day
- Graduation
- Father's Day
- National Chocolate Day!
- National Donut Day!

Find Something to Celebrate All Year 'round!

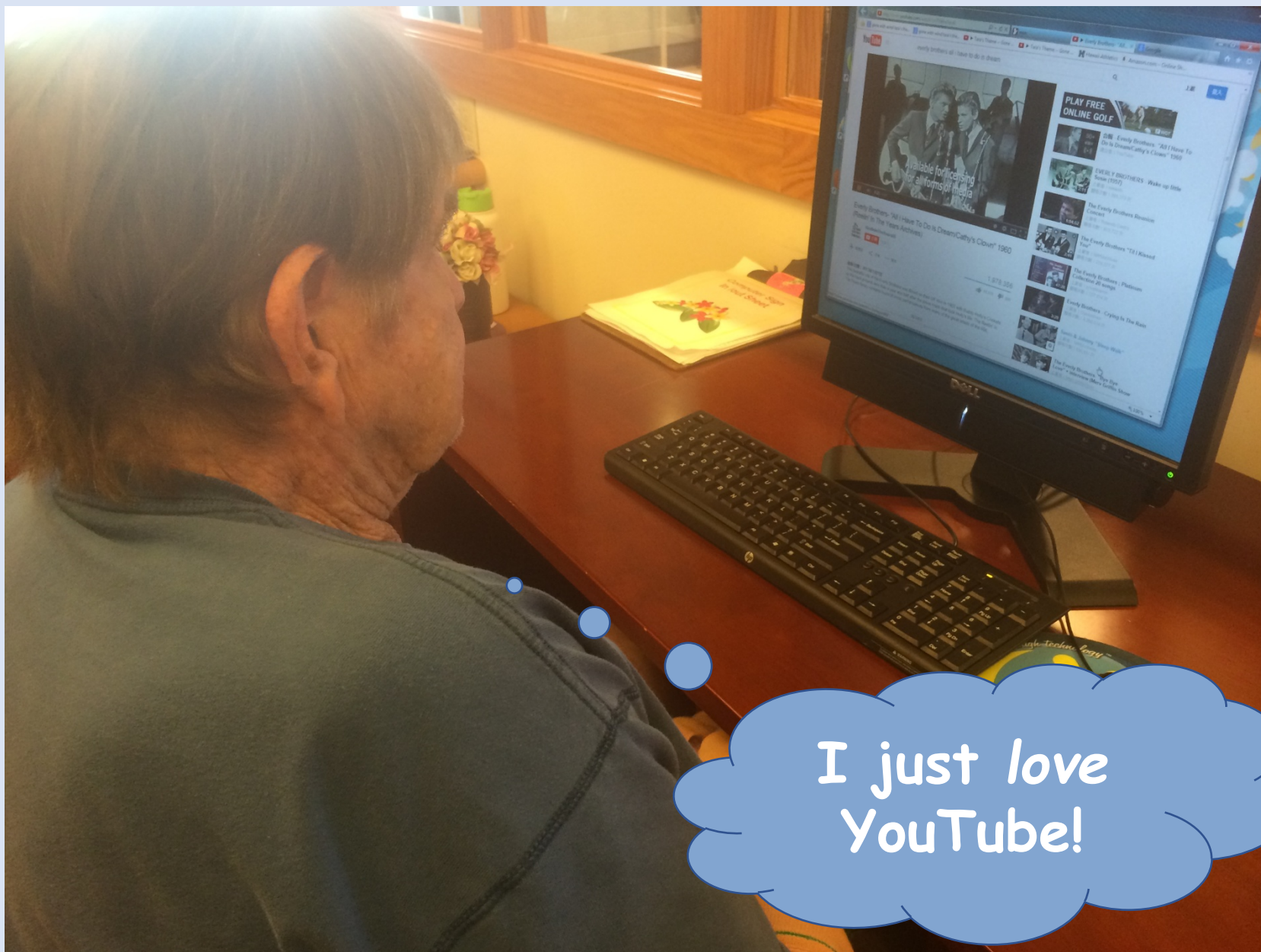
Music Therapy

INTERACTIVE!



Hale Kuike, Pierre Grill

Examples:
Music along with...
Singing
Playing instrument
Tapping Rhythm
Moving
Dancing
Exercise
Reminiscence
Live Music



Maunalani

Create Moments of Joy

*a person with dementia lives
from*

moment to moment...

...Focus your energies on

*Creating
Moments*

of JOY



-- Jolene Brackey

Put your “Dementia Team” together

- This is a “team sport”- Create a safe “pod” of caregivers.
- Create a game plan together
 - Who covers Monday, Tuesday, morning, afternoons, etc.
 - Who helps with doctor’s appointments?
 - Are weekends different?
- Build in personal time
- Join a Support Group
- Monitor yourself for caregiver burnout



Make a Daily Plan

Try to create a
predictable schedule

This will also allow
others to help!

Daily plan example (for early- to middle-stages of the disease)

Morning

- Wash, brush teeth, get dressed
- Prepare and eat breakfast
- Have a conversation over coffee.
- Discuss the newspaper, try a craft project, reminisce about old photos
- Take a break, have some quiet time
- Do some chores together
- Take a walk, play an active game

Afternoon

- Prepare and eat lunch, read mail, wash dishes
- Listen to music, do crossword puzzles, watch TV
- Do some gardening, take a walk, visit a friend
- Take a short break or nap

Evening

- Prepare and eat dinner, clean up the kitchen
- Reminisce over coffee and dessert
- Play cards, watch a movie, give a massage
- Take a bath, get ready for bed, read a book

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)	_____	_____	_____
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)	_____	_____	_____
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)	_____	_____	_____
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)	_____	_____	_____
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)	_____	_____	_____
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)	_____	_____	_____
There have been other demands on my time (For example: other family members need me)	_____	_____	_____
There have been emotional adjustments (For example: severe arguments about caregiving)	_____	_____	_____
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)	_____	_____	_____
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)	_____	_____	_____
There have been work adjustments (For example: I have to take time off for caregiving duties)	_____	_____	_____
Caregiving is a financial strain	_____	_____	_____
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)	_____	_____	_____
[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]			
Total Score =			

Be aware of Caregiver Burnout: Modified Caregiver Strain Index

POSSIBLE IMPACT ON

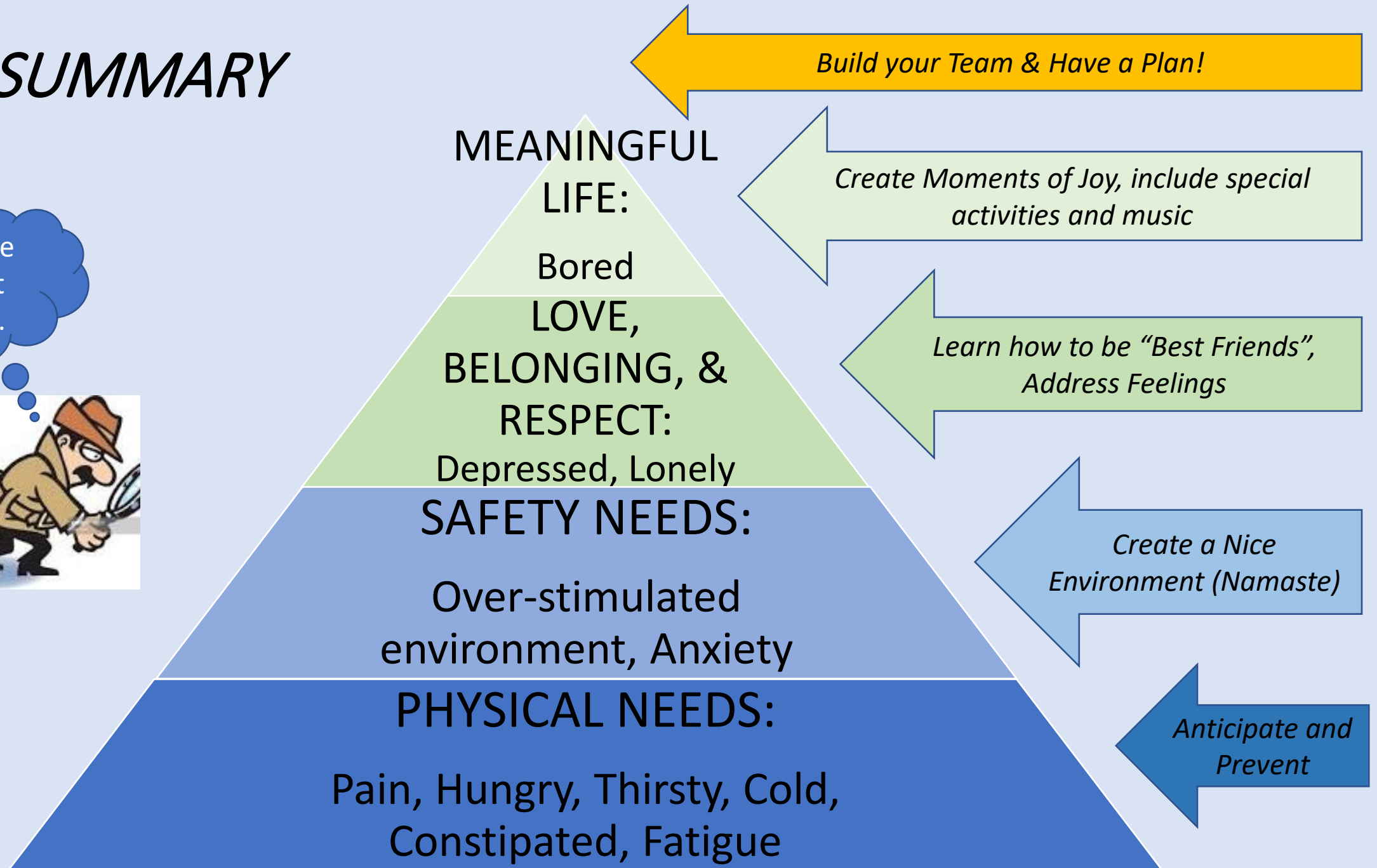
- ☐ Your work/financial situation
- ☐ Your family
- ☐ Your health
- ☐ Your emotions (Increased risk for depression and anxiety)
- ☐ Increased risk for elder neglect or abuse

Do Not Be Afraid to Ask for Help

- Have a “Plan B”, in case some caregivers gets sick
- Alternatives: hire a caregiver, adult day care
- Care home, nursing home- may have limited access for visitation.
- GOAL: your loved one should get the care they need.

THE SUMMARY

Find the
unmet
need...



Questions?



5 Questions

1. Behaviors are an attempt to communicate unmet needs. **True** or False
2. It is important to pay attention to the environment to make sure it is calming and safe **True** or False
3. What persons with dementia get anxious, the best approach is to validate and address their feelings. **True** or False
4. When persons with dementia begin resisting help, you should tell them that you are in charge and they must listen to you. True or **False**
5. Studies have shown that music therapy can improve dementia behaviors **True** or False