

UNDERSTANDING DEMENTIA



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Organizations

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TRAINING OVERVIEW

1. Defining dementia
2. Dementia's effects on daily life
3. Role of SADS in dementia care
4. Supporting someone with dementia
5. Planning activities for someone with dementia

SELF CHECK-IN

Have you ever known someone with dementia?

What was it like?

What did you find rewarding,
challenging, or interesting?

How did you feel working
with that person?





DEFINING DEMENTIA

Dementia is an umbrella term that includes a range of both reversible and irreversible conditions.

Examples of types of irreversible dementia:

- Alzheimer's Disease
- Vascular Dementia
- Frontotemporal Dementia (FTD)
- Dementia with Lewy Bodies (LBD)
- Others

Reversible dementias can include things such as medication side effects, substance abuse, or even depression.

Differential diagnosis is **CRITICAL!**

Note that dementia is **NOT** the same thing as Alzheimer's Disease!

TYPES OF DEMENTIA



KEY FACTS ABOUT DEMENTIA

- Symptoms can look very different between each diagnosis
- Progression is unpredictable (months to even years)
- Two people with the same diagnosis may be nothing alike

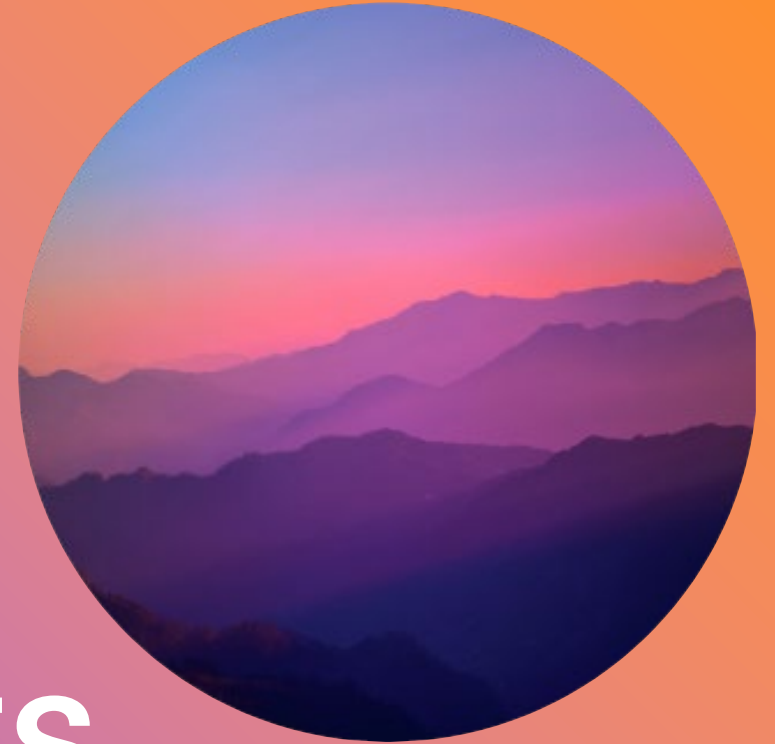
An estimated 450,000 New Yorkers are affected by some kind of cognitive change. Prevalence is expected to increase as the Baby Boomer Generation ages.

What about psychosocial quality of life concerns?

- Social isolation
- Loneliness
- Boredom
- Depression
- Anxiety

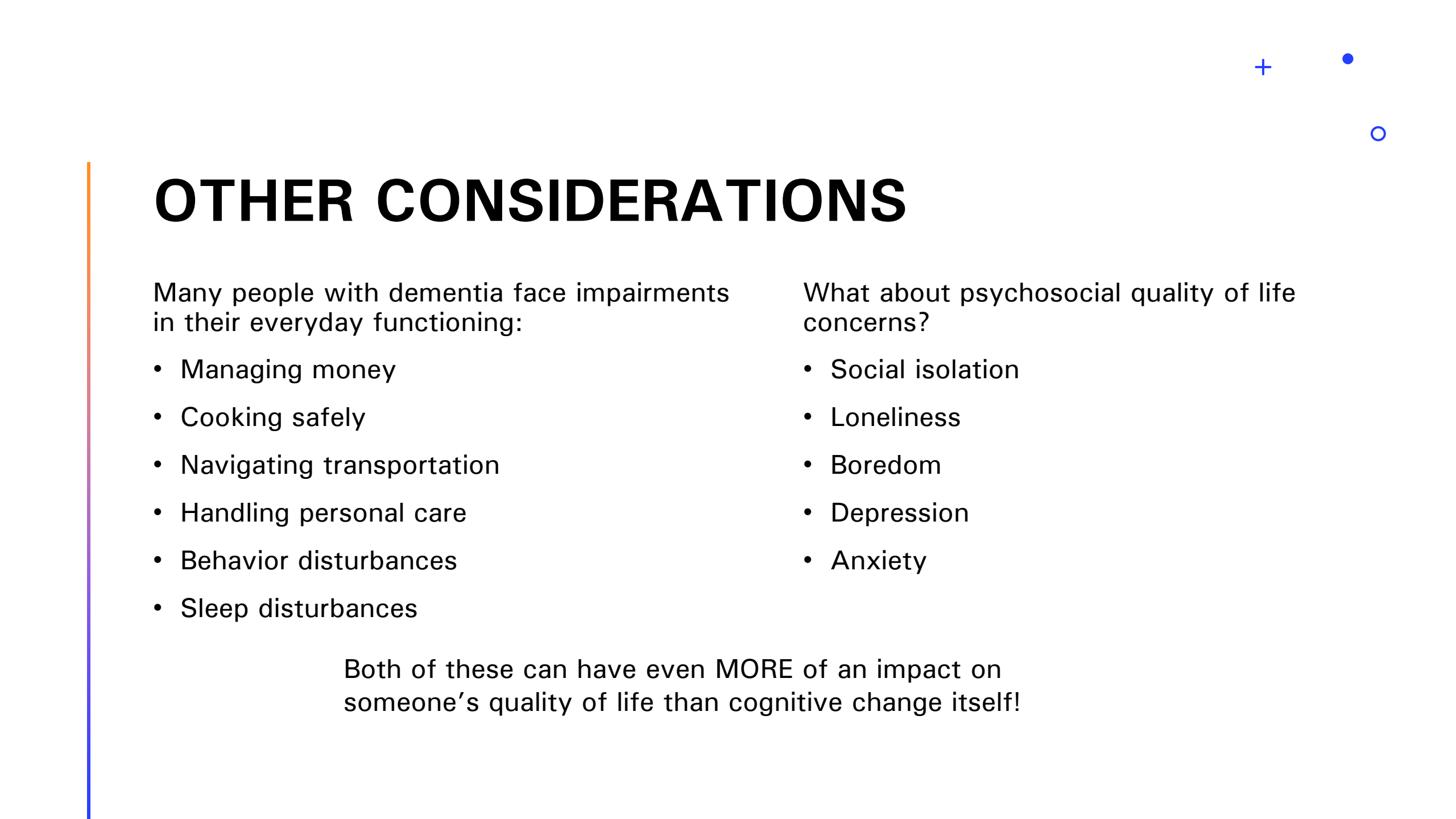
These can have even MORE of an impact on someone's quality of life!

DEMENTIA'S EFFECTS ON DAILY LIFE



COGNITIVE CHANGES - THE FIVE A'S

Issue	Meaning	Examples
Amnesia	Difficulty with memory and recall	Forgetting Repeat questioning
Aphasia	Difficulty with speech and language	Expressive aphasia Receptive aphasia
Apraxia	Difficulty with tasks and sequencing	Processing speed Doing things "out of order"
Ataxia	Difficulty with movement and muscle control	Balance and gait issues Involuntary or uncontrolled movements
Agnosia	Difficulty with perception and recognition	Mistaking one person for another Difficulty with shadows/dark spaces



OTHER CONSIDERATIONS

Many people with dementia face impairments in their everyday functioning:

- Managing money
- Cooking safely
- Navigating transportation
- Handling personal care
- Behavior disturbances
- Sleep disturbances

What about psychosocial quality of life concerns?

- Social isolation
- Loneliness
- Boredom
- Depression
- Anxiety

Both of these can have even MORE of an impact on someone's quality of life than cognitive change itself!



CO-MORBIDITIES

Many people with dementia also face other chronic challenges, including:

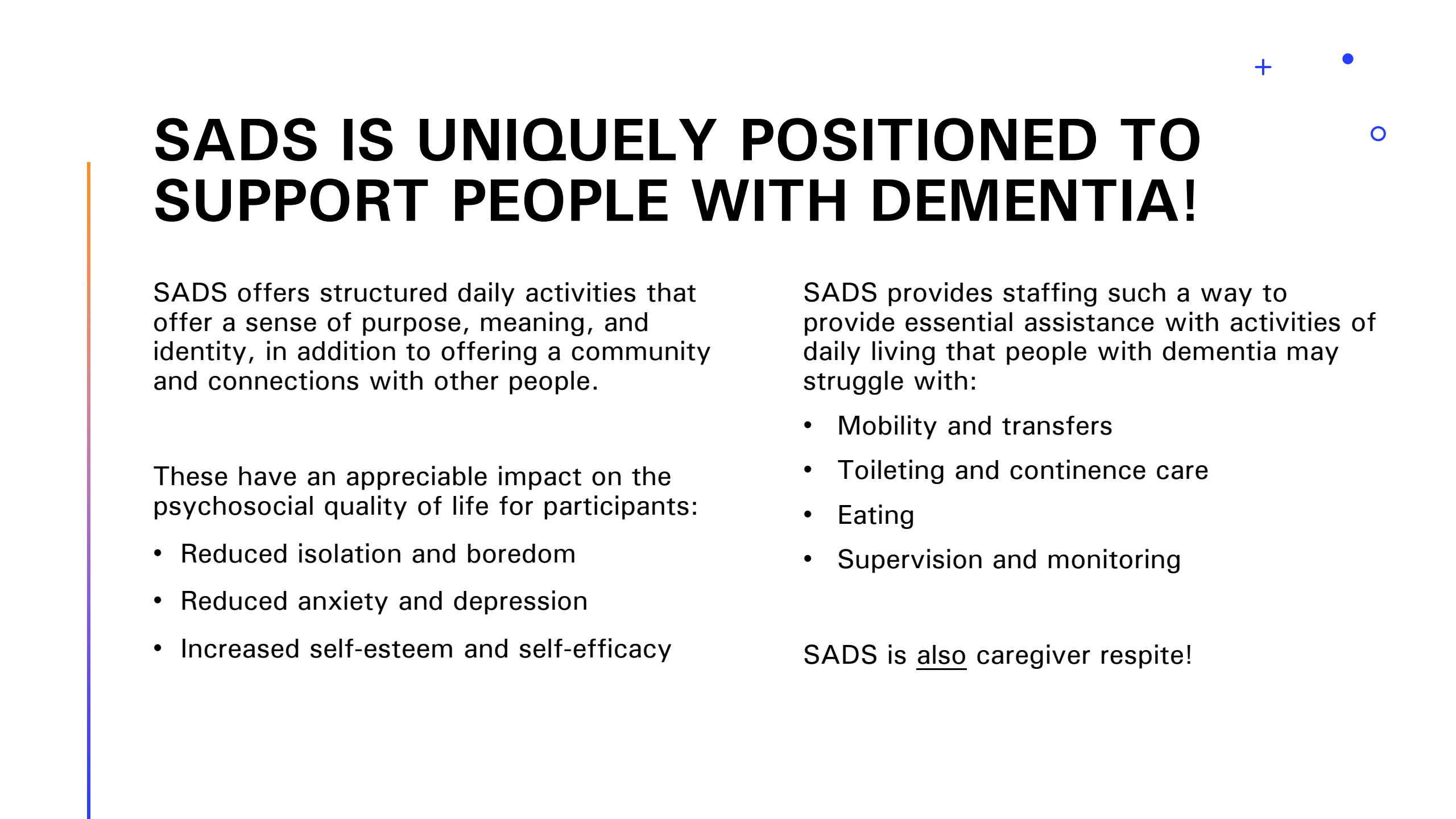
- Medical conditions
- Mental health conditions
- Hearing and vision loss
- Stamina level
- Deficits in attention, impulse control, and judgement
- Chronic pain
- Others

Treating a co-morbidity can appreciably improve cognition and influence behavior.

Changes in the environment can also influence cognition and functioning.



THE ROLE OF SADS IN DEMENTIA CARE



SADS IS UNIQUELY POSITIONED TO SUPPORT PEOPLE WITH DEMENTIA!

SADS offers structured daily activities that offer a sense of purpose, meaning, and identity, in addition to offering a community and connections with other people.

These have an appreciable impact on the psychosocial quality of life for participants:

- Reduced isolation and boredom
- Reduced anxiety and depression
- Increased self-esteem and self-efficacy

SADS provides staffing such a way to provide essential assistance with activities of daily living that people with dementia may struggle with:

- Mobility and transfers
- Toileting and continence care
- Eating
- Supervision and monitoring

SADS is also caregiver respite!

SUPPORTING AND ENGAGING SOMEONE WITH DEMENTIA





CORE CONCEPTS

Rules of thumb:

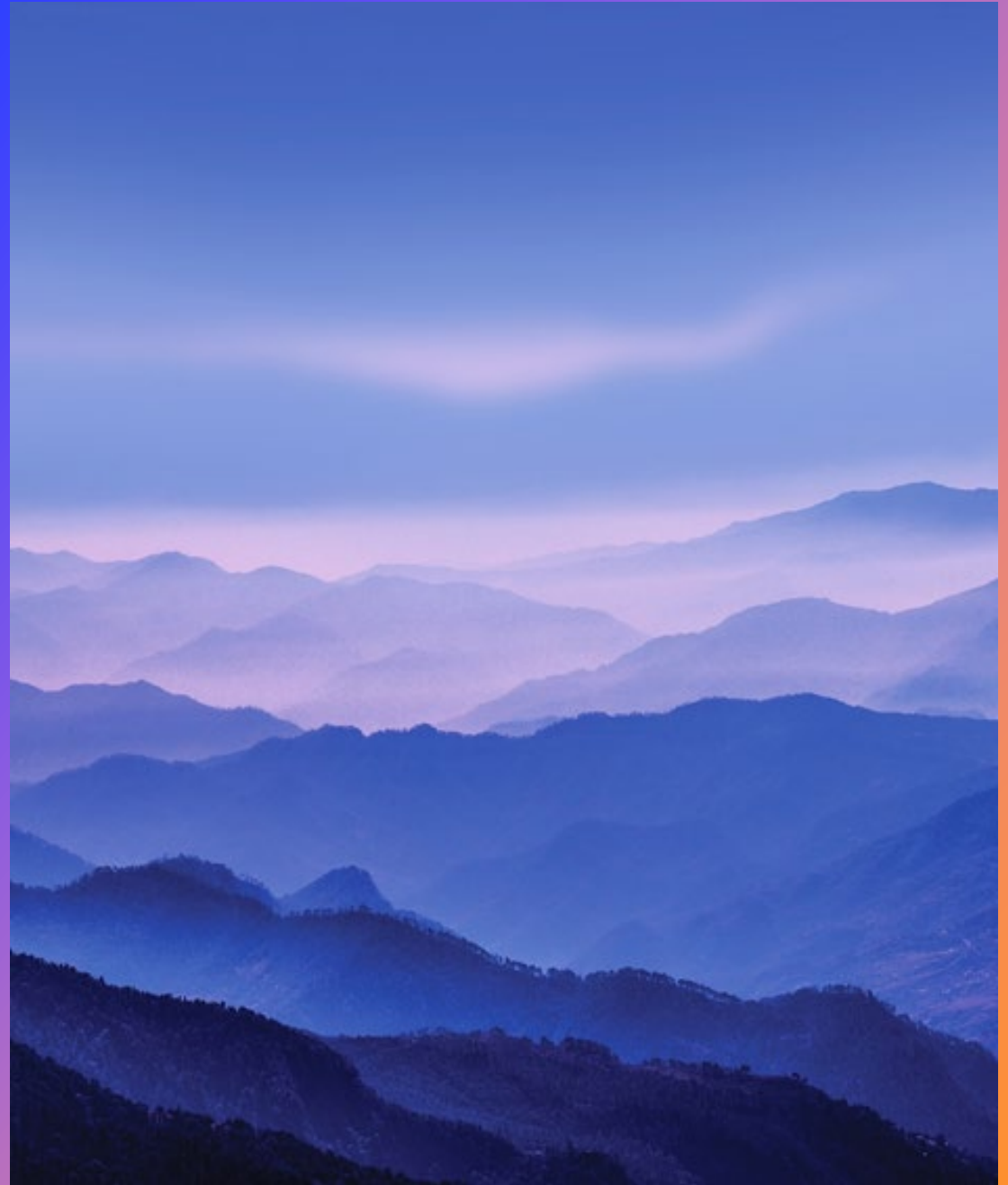
- Connect BEFORE you correct (more on this later)
- Do not argue with the brain
- Feelings matter more than facts
- Meet someone where they are

Practical strategies for everyday care:

- Use simple and concrete language
- One question or instruction at a time
- Avoid quizzing (e.g., “do you recall...”)
- Validate emotions rather than accuracy
- Redirect rather than confront
- It is easier to change the environment than a person’s behavior

REMEMBER THIS!

Frustration is the
opposite of fun!



THE “ICARE” FRAMEWORK

DO	DON'T	Consideration
Include	Isolate	Arrangement of space Skipping
Connect	Correct	There is no “right” or “wrong”
Adapt	Assume	Offer accommodations for activities for people of all abilities
Relax	Rush	“The 30 second rule”
Engage	Entertain	Active vs. passive participation

WHAT KINDS OF ACTIVITIES?

Type of Activity	Examples
Physical	Gentle stretching, guided exercise (Tai Chi, Chair Yoga), balloon toss
Social	Reminiscing, guided conversation topics, creative storytelling
Cognitive	Trivia, word games, memory prompts
Creative	Arts and crafts, musicmaking, sing-along, dance
Occupational	Horticulture, food making, helping others
Recreational	Group games, BINGO

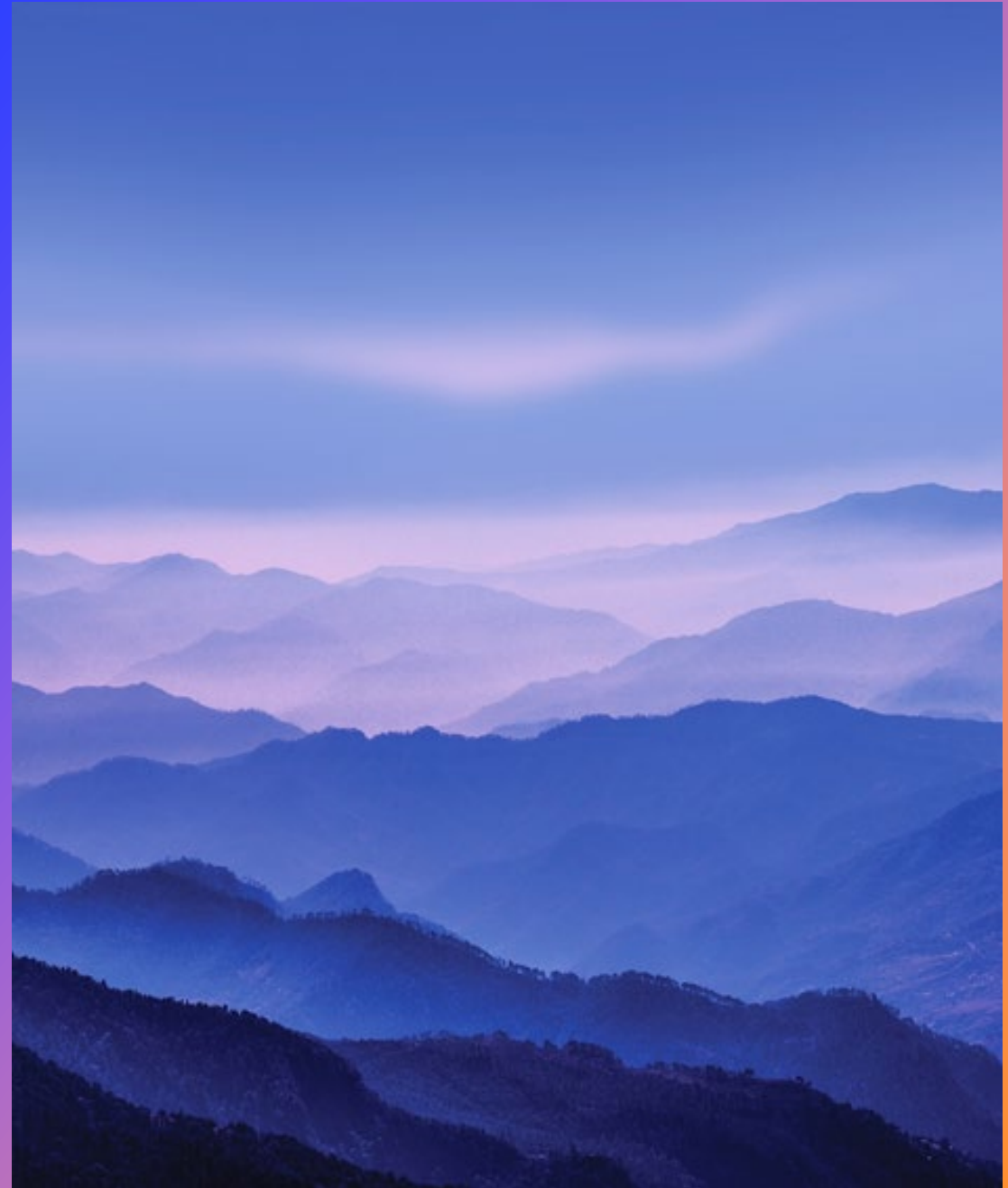
An activity can be more than one thing!

WHAT IF SOMEONE DOES NOT PARTICIPATE?

Participation is a function of **three** factors: $P = M \times O \times C$

1. Motivation
2. Opportunity
3. Capacity

Assess *which* factor is missing and support accordingly.





A WORD ABOUT CAREGIVER SUPPORT

- Caregiver stress is real and cumulative
 - Physical symptoms
 - Psychological symptoms
- Caregiver guilt is common and corrosive
- Asking for help is not failure
 - Many caregivers struggle to reach out and may only do so at a breaking point or crisis situation

Remember: You cannot pour from an empty cup – caring for someone with dementia pokes holes in the cup!

CARING FOR THE CAREGIVER

VIGNETTES



Ruth asks every few minutes, “What time are we leaving?” She gets an answer every time, but she continues to ask, leaving others feeling frustrated and helpless.

Common reactions:

- “I just told you”
- Correcting and pointing out repetition
- Ignoring

Will these support Ruth?

What are some strengths-based reframes and supportive approaches that may help Ruth’s caregivers?

Responding to the feeling, offering grounding, providing a visual cue or routine

#1

“SHE KEEPS
ASKING THE SAME
QUESTION OVER
AND OVER AGAIN”

Xavier resists showering and becomes agitated when prompted. This is interpreted as stubbornness and noncompliance.

Common reactions:

- Insisting
- Escalating tone and urgency
- It is a “behavior problem”

Will these support Xavier?

What are some strengths-based reframes and supportive approaches that may help Xavier’s caregivers?

Offering choices, using familiar language, adjusting the environment, trying again later

#2

“HE REFUSES TO TAKE A SHOWER”

Frances insists that she must leave right now to pick up her children at school – who are actually adults.

Common reactions:

- “Your kids are grown up”
- Escalating tone and urgency
- It is a “behavior problem”

Will these support Frances?

What are some strengths-based reframes and supportive approaches that may help Frances’s caregivers?

Validating the feeling, engaging her caregiving instinct, redirecting meaningfully

#3

“SHE THINKS SHE NEEDS TO PICK UP THE KIDS”

Samuel rarely speaks and does not respond to questions. People assume he is disengaged or “not there.”

Common reactions:

- Talking over him
- Disengaging completely
- Assuming lack of awareness

Will these support Samuel?

What are some strengths-based reframes and supportive approaches that may help Samuel’s caregivers?

Watching for nonverbal communication, sitting at eye level, using music and touch shared activities, narrating gently

#4

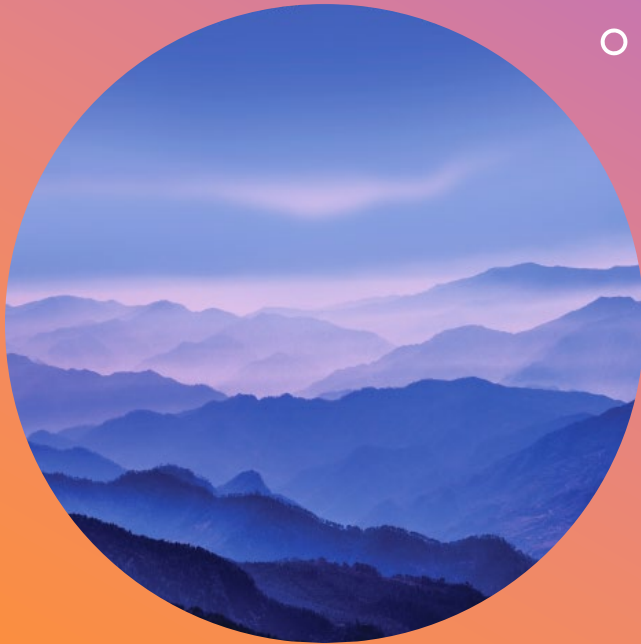
“HE DOES NOT REALLY TALK MUCH ANYMORE”

RESOURCES AND FURTHER READING



SUGGESTED WEBSITES AND ORGANIZATIONS

- **Caring Kind NYC** – excellent NYC area resource
<https://caringkindnyc.org> – 646.744.2900
- **Alzheimer's Foundation of America** – based in NYC, has national reach
<https://alzfdn.org> – 866.232.8484
- **Alzheimer's Association** – local chapters nationwide
<https://alz.org> – 800.272.3900



THANK YOU

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