

# Dementia Q&A Panel

Joseph E. Gaugler, PhD

Robert L. Kane Endowed Chair in Long-Term Care & Aging

Director, Center for Healthy Aging and Innovation

Director, BOLD Public Health Center of Excellence on  
Dementia Caregiving

# Land acknowledgment

*The University of Minnesota Twin Cities is located on traditional, ancestral, and contemporary lands of Indigenous people. I acknowledge with gratitude the Land itself and the People. I take to heart and commit through action to learn and honor the traditional cultural Dakota Values: Courage, Wisdom, Respect and Generosity.*



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UNIVERSITY OF MINNESOTA

ROBERT L. KANE ENDOWED CHAIR IN LONG-TERM CARE AND AGING

# Dementia Q&A Panel

## Have Questions About Dementia? We will Try to Answer Them!

March 17, 2022 | 3:00-4:30pm CST | Zoom

Join an interdisciplinary panel in  
discussing and answering questions related  
to living with and caring for dementia, and  
the key issues that often come up.



Hosted by Dr. Joseph Gaugler, Robert L. Kane Endowed  
Chair in LTC and Aging at the University of Minnesota.

Register and submit questions at:  
<https://bit.ly/DementiaQandA>



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@UMNCHAI



**Amy Busker**  
Geriatric Pharmacist



**Jill Cigliana**  
Occupational  
Therapist



**Robbin Frazier**  
Cultural Expert



**Sara Ochoa**  
Physical Therapist



**James Pacala**  
Family Physician and  
Geriatrician



**Lucas Spaeth**  
Elder Law Attorney

# Improving Antipsychotic Prescribing: Focus on Behavioral Symptoms in Dementia

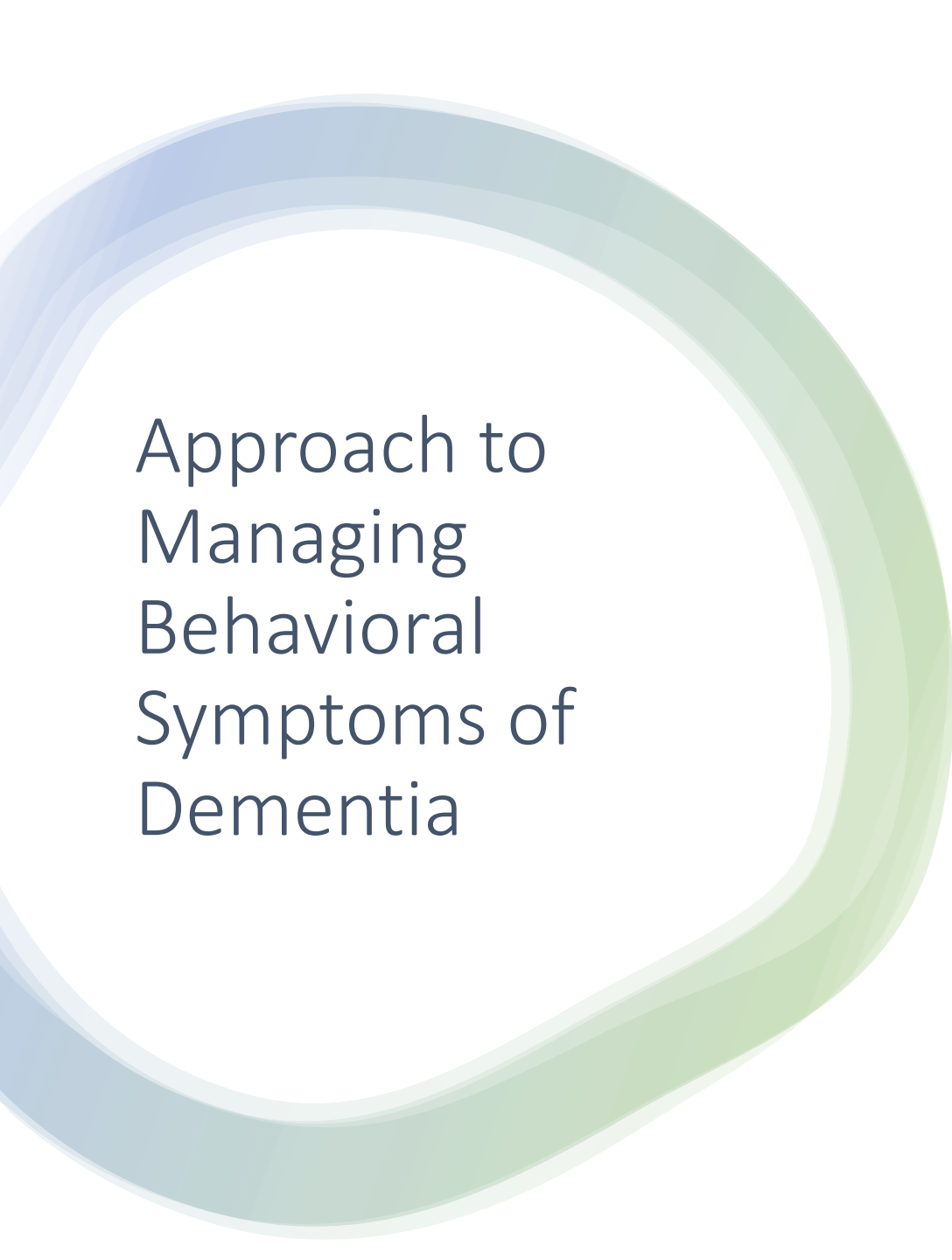
Amy Busker, Pharm.D.,BCGP

3/17/22

## Choosing Wisely (AGS recommendation):

**Don't use antipsychotics as the first choice to treat behavioral and psychological symptoms of dementia.**

People with dementia often exhibit aggression, resistance to care and other challenging or disruptive behaviors. In such instances, antipsychotic medicines are often prescribed, but they provide limited and inconsistent benefits, while posing risks, including over sedation, cognitive worsening and increased likelihood of falls, strokes and mortality. Use of these drugs in patients with dementia should be limited to cases where non-pharmacologic measures have failed and patients pose an imminent threat to themselves or others. **Identifying and addressing causes of behavior change can make drug treatment unnecessary.**



# Approach to Managing Behavioral Symptoms of Dementia

- Identify and address cause of behavior change
  - Describe the behavior
  - Consider potential triggers and reversible causes
    - Environmental, physical problems/needs, medical, psychiatric, caregiver factors
- Non-drug strategies first!
  - Treat physical/medical problems - ex, dehydration, infection, medication side effects, pain, insomnia, hunger, etc.
  - Clear communication, redirection, offer enjoyable/meaningful activities, day-to-day structure, person-centered care
  - Adjust caregiver approaches
  - Adapt/change environment
  - Music therapy, aromatherapy, massage, reminiscence therapy, etc.

# When non-drug interventions have failed...

- Appropriate antipsychotic treatment targets:
  - Aggression, agitation, or psychotic symptoms
    - Causing severe distress
    - Risk of harm to self or others
- Shared decision making continues
  - Discuss overall goals, specific goals of treatment, risks and benefits
- Non-drug interventions continue
- Second generation antipsychotics preferable (ex. quetiapine, risperidone, etc.)
  - Start low, go slow! Use minimum effective dose
  - Monitor for effectiveness and adverse effects
    - Taper and discontinue if no benefit after 4 weeks
    - If adverse effect, weigh risk vs benefit; discontinuation may need to be considered
    - If adequate response, taper should be attempted within 4 months of treatment – monitor closely



# Resources

- ABIM Foundation. *Choosing Wisely*. American Geriatric Society: Ten Things Physicians and Patients Should Question. Last reviewed 2021.
- Fazio et al. What is Really Needed to Provide Effective, Person-Centered Care for Expressions of Dementia? Guidance from the Alzheimer's Association Dementia Care Provider Roundtable. *JAMDA* 21, 2020, 1582-1586.
- Reus et al. The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia. *Am J Psychiatry* 173:5, May 2016.
- SAMHSA, CMS, HRSA, ACL. Guidance on Inappropriate Use of Antipsychotics: Older Adults and People with Intellectual and Developmental Disabilities in Community Settings.
- Scales et al. Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia. *The Gerontologist*, Volume 58, Issue suppl\_1, February 2018, S88-S102, <https://doi.org/10.1093/geront/gnx167>

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# Memory Care Home Solutions

## Non-pharmacological Dementia Intervention at Home

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Jill Cigliana, MSOT, OTR/L



# Memory Care Home Solutions

- **Community-based non-for-profit organization founded in 2002**
- **Mission:**  
To extend and improve quality time at home for people living with dementia and their families



# Behavioral Intervention Evidence Base



Thomas  
Jefferson  
University

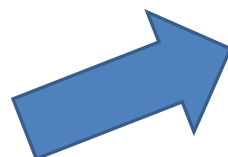
## Skills2Care

Care partner training to manage  
behaviors and maximize function



## Tailored Activity Program

Prescribed activities for people  
with dementia to decrease  
behavioral problems



## COPE

Behavior  
Function  
Activity  
Care partner well-being



# Treat the Care Dyad



Identify preserved strengths, roles, and routines



Home and environmental Assessment



Teach a problem solving approach

e.g., DiZazzo-Miller et al 2017; Gitlin, Cigiana, Cigiana, & Pappa, 2017; Gitlin & Hodgson, 2015; Gitlin & Rose, 2014; Gitlin et al., 2010., etc.

# How to support aging in place with dementia?

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Identify supports for person with dementia and care partner

- Family and Friends
- Alzheimer's Association and Area Agency on Aging

Modify the home for safety and success with the daily routine

- Consider help for driving, meal prep, finances and medication management
- Clear clutter and reduce fall risks
- Ask your doctor for a referral to OT and PT

Connect to group and individualized evidence-based programs in your area

- Groups: Savvy Caregiver, Cognitive Stimulation Therapy, Powerful Tools, Support
- Individual: Skills2Care, REACH, Tailored Activity Program, COPE



# When is it time to transition to residential care?



## Never???

- When there are family/friend care partners who have support PLUS formal supports including home health, palliative care, hospice, accessibility, paid in-home care, and equipment

## When the function and behaviors become too difficult for the care partner to manage

- Are both the person with dementia and care partner **safe**?
- Are both people comfortable with the care tasks, from a **dignity** perspective?
- Ask **formal supports** lacking?

## When the care partner has her/his own health issues or outside demands

- Mental health concerns – chronic stress
- Other family members who need care or work responsibilities
- Physical health limitations – arthritis, heart conditions, diabetes, etc..

# We cannot change the PLWD, but we can change.....

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Our Approach

The Environment

Tasks and Activities



# Resistance to bathing?

Approach	Environment	Activity
<p>Assist from dominant side</p> <p>Get low/eye level or below</p> <p>Hand under hand</p> <p>Describe one step at a time only</p> <p>Slow and gentle</p>	<p>Keep bathroom very warm</p> <p>Adaptive Equipment:</p> <ul style="list-style-type: none"> <li>• Shower chair or transfer bench</li> <li>• Hand-held shower with mounting bracket</li> <li>• Grab bars</li> </ul> <p>Visual contrast in shower area</p>	<p>Keep body parts covered that aren't being washed</p> <p>Move to bed bathing if the shower is not safe or is too upsetting</p> <p>Do all set-up in advance to remain focused on the PLWD (products, extra towels, robe, clothes)</p> <p>Reduce frequency of bathing *focus on peri care</p>

Join MCHS!

6 hours of Continuing  
Education in  
Dementia Best  
Practice

April 8, 2022

# Dementia Hacks 2.0

Solutions for Every Stage

Virtually presented by:



SAINT LOUIS UNIVERSITY  
SCHOOL OF MEDICINE



04/08  
2022



[www.memorycarehs.org/ceu](http://www.memorycarehs.org/ceu)



MEMORY CARE  
HOME SOLUTIONS®



**MEMORY CARE**  
**HOME SOLUTIONS®**

# Thank You!

QUESTIONS? 

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[jcigliana@memorycarehs.org](mailto:jcigliana@memorycarehs.org)

[www.memorycarehs.org](http://www.memorycarehs.org)

# MN School of Public Health: Dementia Q&A Panel

Sara Ochoa, PT, MOMT, CLT





# EXERCISE CONSIDERATIONS FOR ALL STAGES OF DEMENTIA



Keep things moving and interesting



Move in familiar and functional patterns




Keep it simple

# TREATMENT INTERVENTIONS FOR THE DEMENTIA POPULATION: EARLY, MIDDLE AND LATE STAGES









Physical Therapy	Early Stage Dementia Allen Level 4	Middle Stage Dementia Allen Level 3	Late Stage Dementia Allen Level 2
<b>DISCIPLINE SPECIFIC TREATMENT INTERVENTION</b>	<p>Needs structure and routine for increased safety and independence.</p> <p><b>Assistive devices:</b> high 4's can learn to use a new device, low 4's can only use if was part of prior pattern.</p> <p><b>Falls/balance:</b> work on anterior weight shift and dynamic balance activities outside base of support for early falls prevention.</p> <p><b>Gait training:</b> resistive walking with theraband or weights, combine various sensory conditions, obstacle course, changes in cadence to stop/start as cued.</p> <p><b>Therapeutic exercise:</b> open chain (PRE's having patterns continue) and closed chain (marching, knee bends, weight shifting).</p>	<p>Needs to have activities adapted to poor attention span and direction following abilities. Several short 15 minute sessions during the day work best.</p> <p><b>Assistive devices:</b> if not used in prior pattern is unable to learn to use new device.</p> <p><b>Falls/balance:</b> intense work on anterior weight shift and dynamic balance outside base of support for falls prevention.</p> <p><b>Gait Training:</b> resistive walking, combine various sensory conditions, be aware of cognitive tunnel vision 14" in front of face, obstacle course, changes in cadence and stop/start as cues.</p> <p><b>Therapeutic exercise:</b> open chain exercise may be too difficult, closed chain exercises such as marching, knee bends and weight shifting work better.</p>	<p>Dynamic balance to include gait training, reciprocal movements, and turning. Sitting balance to improve trunk control. Lower extremity weight bearing activities to improve/maintain pivot transfer abilities. Assisted ambulation with low Z's. Resistive ambulation or obstacle course with high Z's.</p>


# TEEPA SNOW: THE LIVING GEMS



## The LIVING GEMS®

The GEMS model recognizes the dynamic nature of the human brain and its abilities. Unlike other cognitive models, it acknowledges that everyone's abilities can change in a moment. Modifying environments, situations, interactions, and expectations will create either supportive positive opportunities or result in distress and a sense of failure. Just as gemstones need different settings and care to show their best characteristics, so do people. Rather than focusing on a person's loss when there is brain change, seeing individuals as precious, unique, and capable encourages a care partnership and is the core of this model. Providing supportive settings for everyone, including care providers, allows them to use what they have to be their best. The GEMS advocate that everyone living with brain change when given the opportunity will shine. Teepa Snow and Positive Approach® to Care Team

<p> <b>SAPPHIRE</b> ~ True Blue ~ Optimal Cognition, Healthy Brain</p> <ul style="list-style-type: none"> <li>• True to self: personal preferences remain basically the same</li> <li>• Can be flexible in thinking and appreciate multiple perspectives</li> <li>• Stress/pain/fatigue may trigger Diamond state: back to Sapphire with relief</li> <li>• Able to suppress and filter personal reactions: chooses effective responses</li> <li>• Selects from options and can make informed decisions</li> <li>• Processes well and able to successfully transition</li> <li>• Aging doesn't change ability: processing slows, more effort/time/practice needed</li> </ul>	<p> <b>AMBER</b> ~ Caught in a Moment of Time ~ Caution Required</p> <ul style="list-style-type: none"> <li>• Focused on sensation: seeks to satisfy desires and tries to avoid what is disliked</li> <li>• Environment can drive actions and reactions, without safety awareness</li> <li>• Visual abilities are limited: focus is on pieces or parts not the whole picture</li> <li>• What happens to or around an Amber, may cause strong and surprising reactions</li> <li>• Enters others' space and crosses boundaries attempting to meet own needs</li> <li>• Has periods of intense activity: may be very curious or repetitive with objects or actions</li> <li>• Care is refused or seen as threatening due to differences in perspective and ability</li> </ul>
<p> <b>DIAMOND</b> ~ Clear and Sharp ~ Routines and Rituals Rule</p> <ul style="list-style-type: none"> <li>• Displays many facets: behavior and perspective can shift dramatically</li> <li>• Prefers the familiar and may resist change: challenged by transitions</li> <li>• More rigid and self-focused: sees wants as needs, when stressed</li> <li>• Personal likes/dislikes in relationships/space/belongings become more intense</li> <li>• Reacts to changes in environment: benefits from familiar, functional/torgiving</li> <li>• Needs repetition and time to absorb new/different information or routines</li> <li>• Trusted authority figures can help: reacts better when respect is mutual</li> </ul>	<p> <b>RUBY</b> ~ Deep and Strong in Color ~ Others Stop Seeing What is Possible</p> <ul style="list-style-type: none"> <li>• Makes use of rhythm: can usually sing, hum, sway, rock, clap, and dance</li> <li>• When moving can't stop, when stopped: can't get moving: needs guidance and help</li> <li>• Big strong movements are possible, while skilled abilities are being lost</li> <li>• Danger exists due to limited abilities combined with automatic actions or reactions</li> <li>• Tends to miss subtle hints, but gets magnified facial expressions and voice rhythms</li> <li>• Can mimic actions or motions, but will struggle to understand instructions/gestures</li> <li>• Able to pick up and hold objects, and yet not know what to do with them</li> </ul>
<p> <b>EMERALD</b> ~ Green and On the Go With a Purpose ~ Naturally Flawed</p> <ul style="list-style-type: none"> <li>• Sees self as able and independent with limited awareness of changes in ability</li> <li>• Lives in moments of clarity mixed with periods of loss in logic/reason/perspective</li> <li>• Understanding and use of language change: vague words and many repeats</li> <li>• Cues and support help when getting to/from places and doing daily routines</li> <li>• Awareness of time, place, and situation will not always match current reality</li> <li>• Strong emotional reactions are triggered by fears, desires, or unmet needs</li> <li>• Needs to know what comes next: seeks guidance and assistance to fill the day</li> </ul>	<p> <b>PEARL</b> ~ Hidden Within a Shell ~ Beautiful Moments to Behold</p> <ul style="list-style-type: none"> <li>• Will frequently recognize familiar touches, voices, faces, aromas, and tastes</li> <li>• Personhood survives, although all other capabilities are minimal</li> <li>• Understanding input takes time: go slow and simplify for success</li> <li>• In care, first get connected by offering comfort then use careful and caring touch</li> <li>• Changes in the body are profound: weight loss, immobility, systems are failing</li> <li>• As protective reflexes are lost, breathing, swallowing, and moving will be difficult</li> <li>• Care partners benefit from learning the art of letting go rather than simply giving up</li> </ul>



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# EXERCISE CONSIDERATIONS: EARLY STAGE

Consider  
environment,  
work at edge of  
public space

## Characteristics

Oriented to person,  
place and  
routine/structure

3-4 step instructions

Poor safety  
awareness

Likes gestures and  
exuberance/

## Exercise ideas

Balance tasks like  
reaching for familiar  
objects while  
standing on foam  
pad or dyna disc

Walking with ankle  
weights or weighted  
vest – consider  
obstacle course  
work

Stop/Start cadence  
on cue

Any motion with a  
familiar pattern like  
clapping, catch,  
marching



# EXERCISE CONSIDERATIONS: MIDDLE STAGE

Poor awareness  
of lower half of  
their body

## Characteristics

Needs lots of positive reinforcement

Poor attention span, catches some words you are saying

If assistive device was not used in prior pattern, may be very difficult to learn

Demonstrate desired task at arms length directly in front of person

## Exercise ideas

Balance tasks like reaching for familiar objects, change base of support

Walking with ankle weights or weighted vest – consider music to assist with cadence and engagement

Focus on standing and wt shift tasks like marching, knee bends and standing working multiple directions

Bed mobility tasks like rolling side to side and getting up safely – can add arm weights or ankle weights to increase the challenge.

# EXERCISE CONSIDERATIONS: LATE STAGE

Go slow and  
watch for  
discomfort

## Characteristics

Present with  
postural insecurity –  
fear of falling

Becomes agitated if  
hurried

Cognitive processing  
is 2-3x slower

Wanders and likes  
to follow people

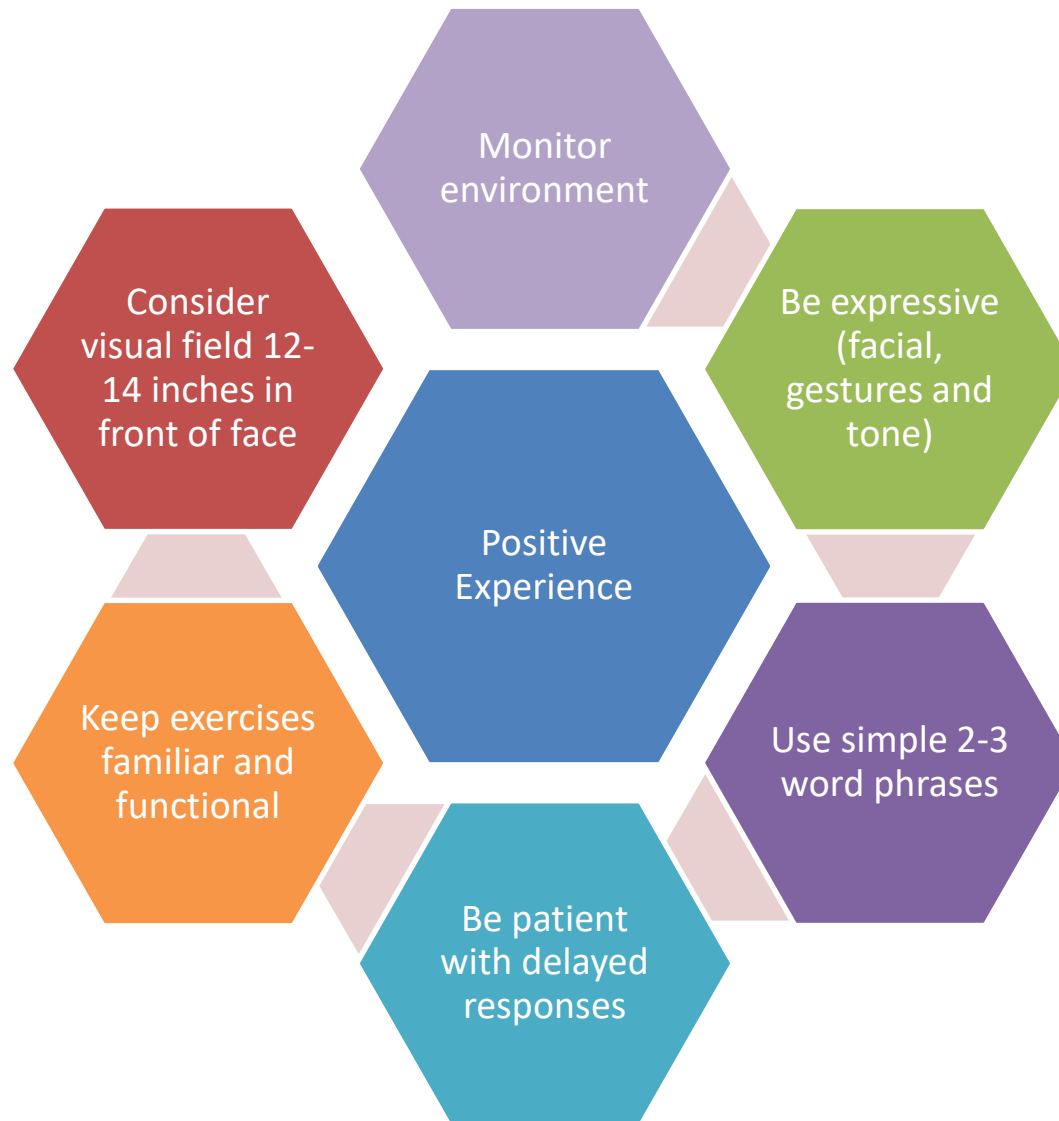
## Exercise ideas

Balance tasks seated  
with feet supported  
– reaching and  
moving items across  
body

May require hand  
hold assist to  
ambulate – hand  
under/over

Focus on trunk  
control tasks;  
consider using large  
physioball

Use persons name  
frequently and  
demonstrate with  
exaggerated  
movements



*Thank you*

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# Center for Healthy Aging and Innovation (CHAI)

*Three themes will be addressed:*

*Culture Considerations when addressing memory and dementia concerns*

*Communications - when, why, who, what*

*Resources - national, local and culturally specific*

*Speaker:*

*Robbin Frazier, CHAI - Associate Director of Equity and Community Engagement [frazi248@umn.edu](mailto:frazi248@umn.edu) | 763-360-7582*



# Cultural Considerations when Addressing Concerns

*My grandfather seems less like the man I spent my summers visiting and shared time with at African American Episcopal church. After not seeing him for two years during the COVID-19 pandemic I was stunned by the changes. When I try to discuss my concerns, everyone ignores me! Why?*

## ❑ Stigma

- ✓ Lack of access to information
- ✓ ADRD association with mental health, myths and taboos often not viewed like a chronic disease

## ❑ Shame

- ✓ Distrust of some health providers
- ✓ Diagnosis triggers immediate loss of independence
- ✓ Expect to be viewed by the lens of the disease

## ❑ Silence

- ✓ Keep information within the family
- ✓ Value, pride and emphasis on individual strength
- ✓ Spirituality plays a large role
- ✓ Lack of cure makes talking about it unnecessary

# Communications

*After speaking with my siblings, we all agree there are red flags with my father's memory and behavior. We have safety concerns about dents in the car bumper, a water shut off notice, and well-done steaks from our chef. When should we say something? How do we talk to Mom and Dad?*

- ☐ Assess the situation
- ☐ Start the Conversation
  - ☐ Who should participate in the conversation to discuss concerns?
  - ☐ What is the best time and place to have this conversation?
  - ☐ How will you approach the conversation?
- ☐ Discuss seeing the doctor together
- ☐ Prepare for the doctor's visits
- ☐ Expectations - multiple conversations and doctors visits

Source: alz.org For Caregiver Resources: Call the Alzheimer's Association 24/7 Hotline 1-800-272-3900

# Conversation Examples

When you've noticed a change in someone else:

- ☐ I've noticed [blank] in you, and I'm concerned. Have you noticed it? Are you worried?
- ☐ How have you been feeling lately? You haven't seemed like yourself.
- ☐ I noticed you [specific example], and it worried me. Has anything else like that happened?

Try the following if you've noticed changes in yourself:

- ☐ Many people find it helpful to bring a trusted friend or family member to the medical evaluation.
- ☐ I think it would give me peace of mind to see a doctor and find out what's going on. Would you be willing to go with me for support?

Source: alz.org Caregiver Resources: Call the Alzheimer's Association 24/7 Hotline 1-800-272-3900



# Conversation Examples

## Discuss the doctor's visit:

- ☐ There are lots of things that could be causing these changes, and dementia may or may not be one of them. Let's see if the doctor can help us figure out what's going on.
- ☐ The sooner we know what's causing these problems, the sooner we can address them.
- ☐ I think it would give us both peace of mind if we talked with a doctor.

## Reach out for help: You're not alone on the journey

- ☐ National Resources
- ☐ State and Local Resources
- ☐ Culturally Specific Resources

Source: [alz.org](http://alz.org) Caregiver Resources: Call the Alzheimer's Association 24/7 Hotline 1-800-272-3900

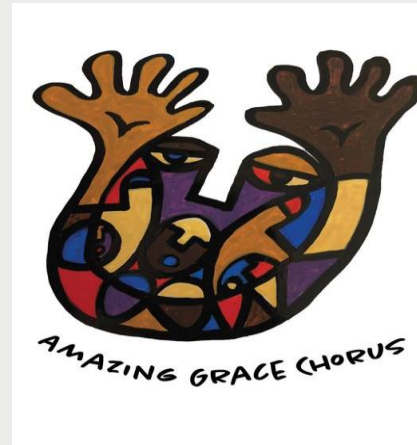
# Caregiving: Resources



[alterdementia.com](http://alterdementia.com)



Centro Tyron Guzman (612) 874-1412  
[www.centromn.org](http://www.centromn.org)  
Latine Adults & Aging Services



[amazinggracechorus@gmail.com](mailto:amazinggracechorus@gmail.com) &  
[www.facebook.com/gracechorusstpaul](https://www.facebook.com/gracechorusstpaul)



# Caregiving Resources

## University of Minnesota, School of Public Health & Center for Health Aging and Innovation

- <https://www.sph.umn.edu/research/centers/chai/>
- [Caring for People with Memory Loss](#) annual conference June 4, 2022
- Caring for People with Memory Loss library [Conference Virtual Library](#)

## Additional resources:

- [Nine steps](#) to respite for Caregivers
- Us Against Alzheimer's [caregiver resources](#)
- Family Caregiving for Diverse Elders [resource hub](#)
- Family Caregiver Alliance [connecting caregivers](#)
- National Adult Day Services Association providing [caregiver support](#)
- US Aging leaders in [aging well at home](#)
- [Caregiving in a Diverse American](#): beginning to understand the systemic challenges facing family caregivers

# Caregiving Resources



## Alzheimer's Association

- Education 10 warning signs, care consultations, difficult conversations, preparing for the doctor's visit, Caregivers for [www.alz.org](http://www.alz.org)

## Minnesota Board on Aging - Trellis and MN Area Agencies on Aging

- <https://trellisconnects.org>
- Minnesota's Senior LinkAge Line® (1-800-333-2433)
- Disability Linkage Line® (1-866-333-2466)
- Veterans Linkage Line™ (1-888-Linkvet)
- Dementia Friends Minnesota <https://actonalz.org/dementia-friends>

# Please complete the webinar evaluation

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## Thank you for attending!

**Joe Gaugler, PhD**  
**School of Public Health**  
**Minneapolis, MN 55455**  
**Phone: 612-626-2485**

<https://www.sph.umn.edu/research/projects/rlk/>



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