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MEMORY CARETM
HOME SOLUTIONS

Adaptive Approaches for Aging in Place

*How to Adapt the Environment and Your
Caregiving Approach for Persons at Risk
for Dementia*

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Objectives

1

Recognize the impact of dementia-related cognitive and behavioral impairments on independence and safety in the home environment.

2

Explore environmental barriers in the home that can cause limitations to the function of an individual with cognitive and/or developmental disability.

3

Identify effective environmental modifications to improve or maintain safety and independence.

To help guide our discussion....

- What professions are represented in our audience today?



Developmental Disabilities: An Aging Population

- Increased life expectancy for those with DD
 - 1931: 22 years.... Now it is 70 years!
 - Living in a variety of community settings
 - At higher risk for dementia



Individuals with DD have higher risk for dementia

- Age
- Health conditions (heart, lung, diabetes, etc.)
- History of brain injury
- Down syndrome
 - Plaques & tangles of Alzheimer's disease are present by age 40 (Lott & Dierssen, 2010)
 - 30% of those in their 50s have dementia (National Down Syndrome Society)
 - More than 80% by age 65 (Hithersay, Hamburg, Knight, & Strydom, 2017)

What is
dementia?



What does dementia look like in individuals with DD? Changes in...

Memory

Attention

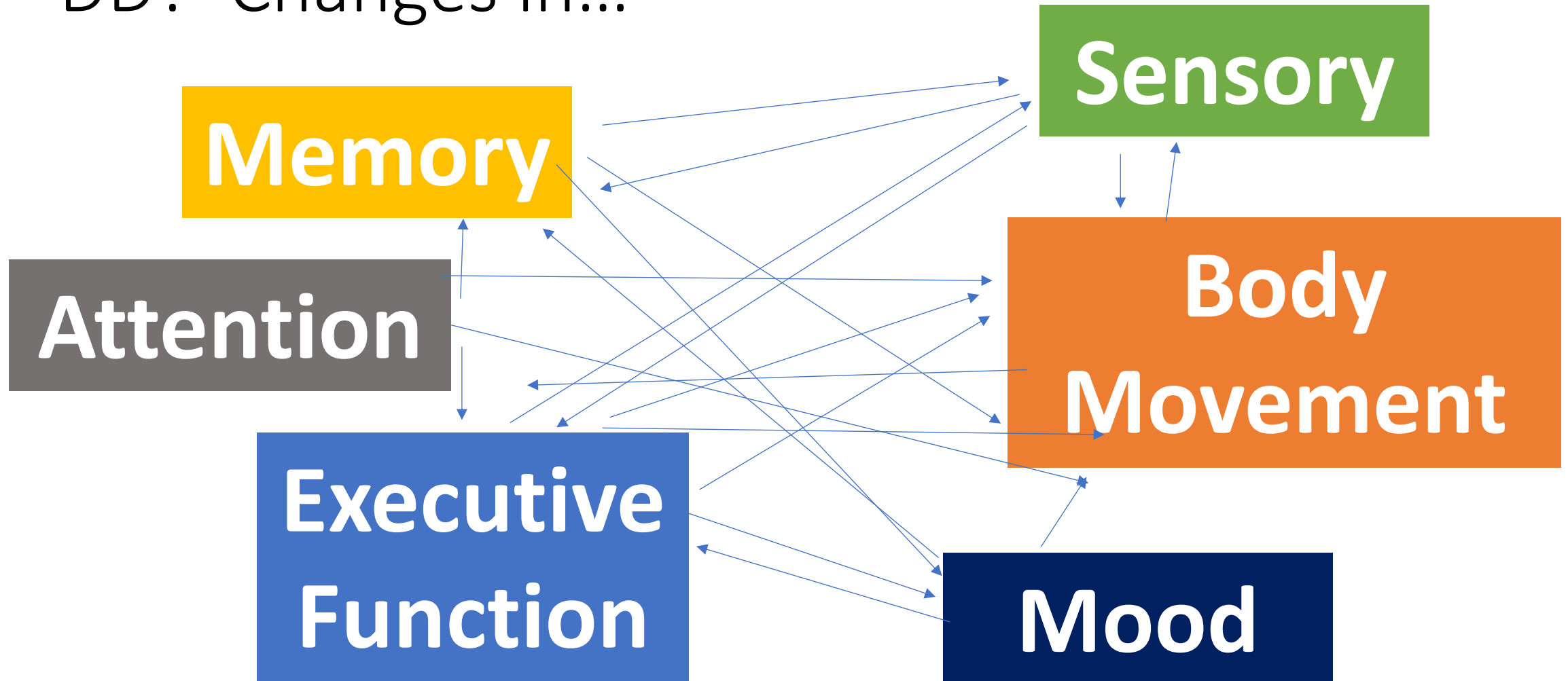
**Executive
Function**

Sensory

**Body
Movement**

Mood

What does dementia look like individuals with DD? Changes in...



Dementia Behaviors

Arguing,
irritability,
complaining

Forgetting to
eat

Not following
through with
agreements

“Sundowning” = being
more confused in late
afternoon/evening

Trying to wander/
leave

Resistant to
receiving
help

Refusing to bathe,
change clothes, take
meds

Confusion
about
time/place



Rule out reversible causes first (UTI, blood sugar, medication errors, dehydration, etc.)



Say NO to the stigma of the “label” of dementia



You already have many of the **TOOLS** you need!!!

Use the person’s interests and strengths
Find motivators
Help with care



You can’t change the person’s brain ... **but what can you change?**

We can not change the person's brain but we can change.....



The Environment



Home Safety for Everyone

- Remove hazardous items, chemicals, medications
- Place unsafe items out of sight
- Safety locks on cabinets or closet doors
- Set water temp in the home to 120F or less
- Disable or unplug appliances



The Environment

Kitchen Safety

- Remove stove knobs
- Place locks on cabinets with unsafe items inside (knives)
- Set Fridge up/ remove spoiled items and declutter and set up for success
- Smoke detectors



The Environment

- Compensate for Visual/Sensory changes
 - The visual system changes as we age and can be significantly impaired in those at risk or with dementia
 - Watch how they move
 - Guarded walking and decreased balance can be from vision/perception changes.
 - Add color contrast
 - Decrease over stimulation (all senses)

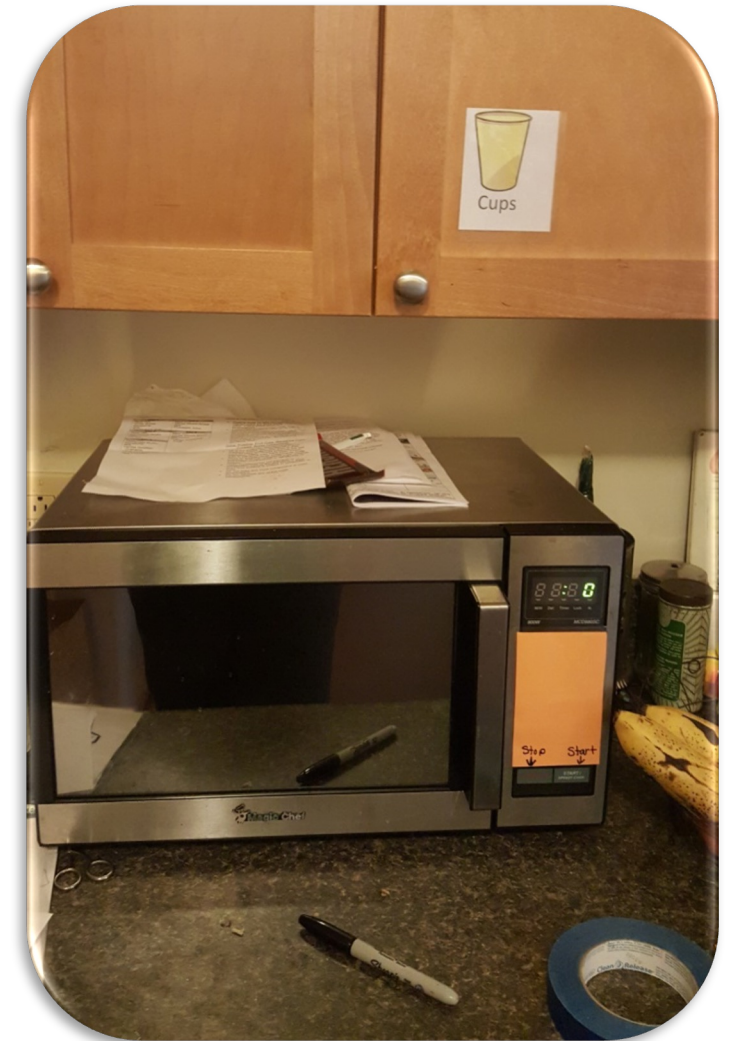
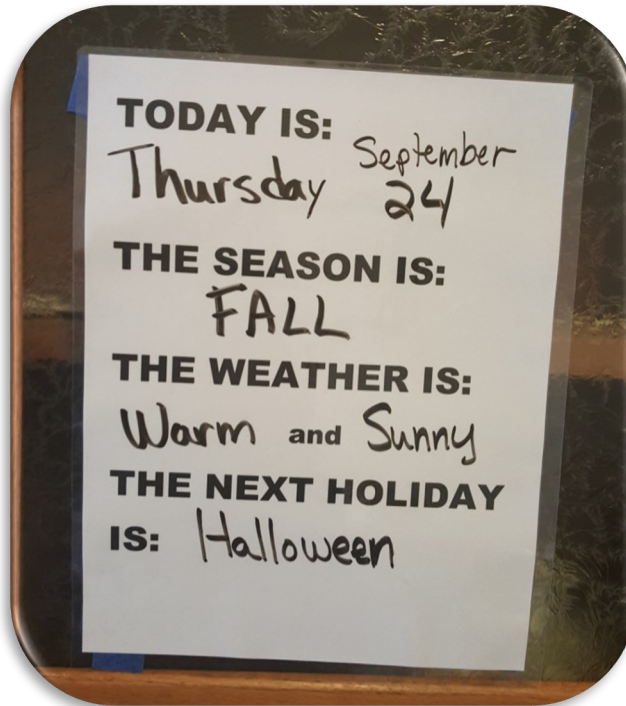


The Environment

Compensation for Memory

Use environmental cues

- Calendars
- Orientation
- Simplify electronics
- “To do” checklist



Our Approach

What We Say Verbally and Physically Can Change Everything!

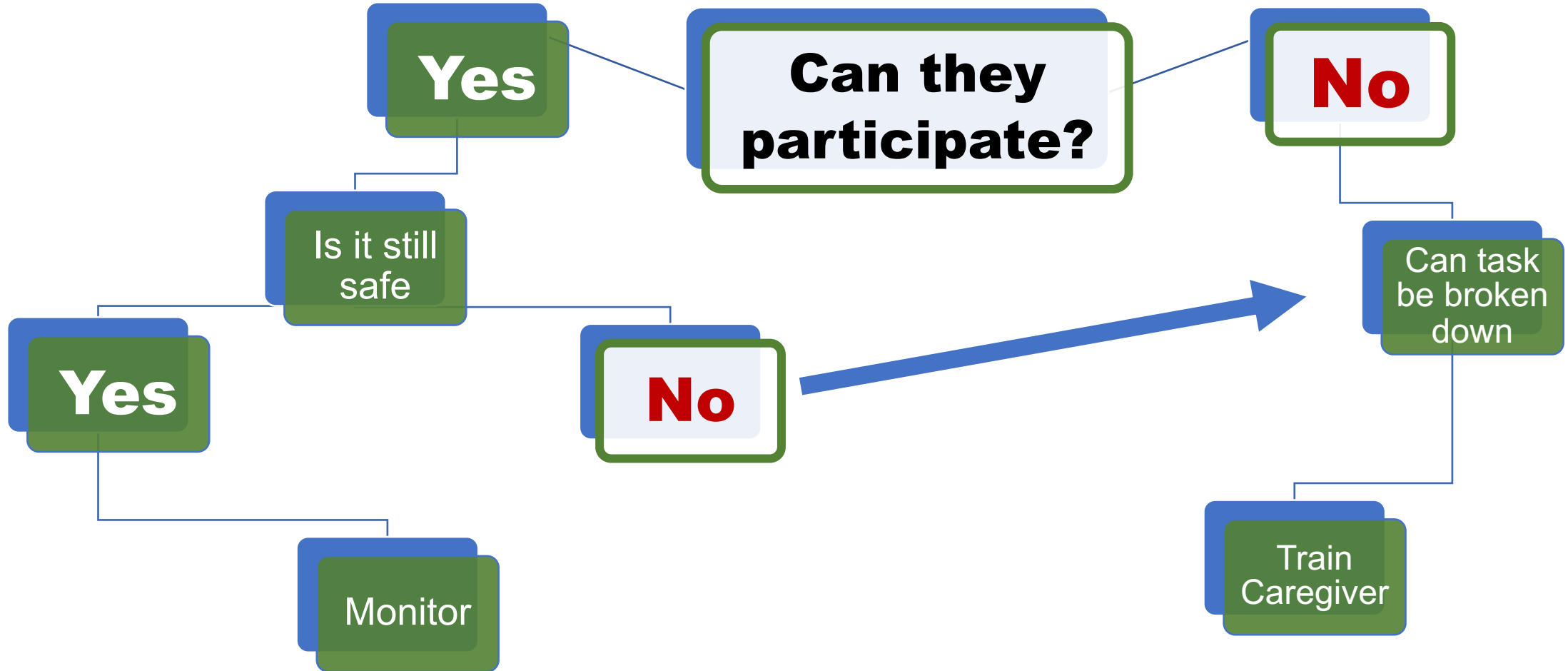
- Do not explain too much or ask if they want to
- Guide them to the steps that need to take place
- Use one step instructions, calm voice, keep simple, verbal, gestural and written cues
- It is not helpful to try to convince a person with dementia of reality.



Our Approach



Task at Hand



Bathing/Dressing Approach

- Do not explain too much or ask “Do you want to?”
- Guide them to the steps that need to take place
- Use one step instructions, calm voice, keep simple
- Verbal, gestural and written cues



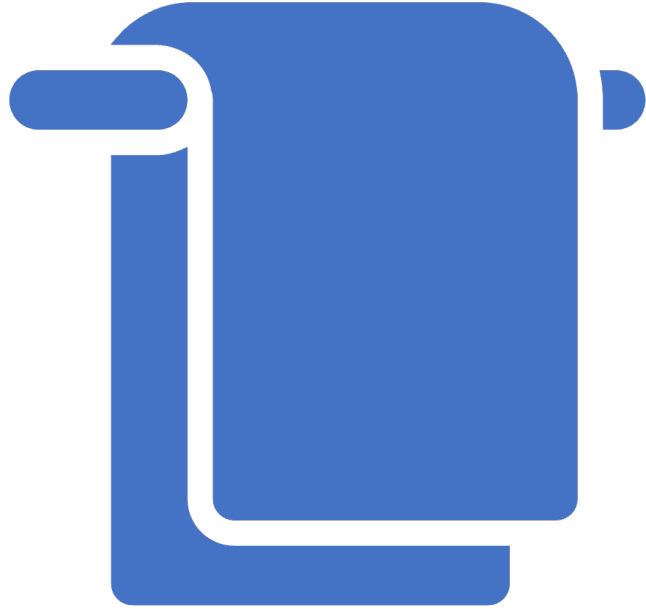
Bathing/Dressing Environment

- Color contrast
- Rug
- Lighting
- Hand held shower head
- Shower chair/bench
- Grab bars
- Reduce clutter/options
- Set water temp to 120 degrees
- Lock up chemicals and cleaners





Bathing/Dressing Task at Hand



- Sensory problems: water feels like PAIN!
 - Try a towel over their skin instead of putting water directly on skin
 - Wraparound bath towels
- Fear
 - Put on gentle or pleasant music
 - Everyone remain calm!
- Simplify, just do step by step
- Minimize verbal directions (make sure you give time to process)

Bathing /Dressing



Fall Prevention Environment

- Reducing clutter
- Clear paths
- Increase lighting, motion lighting
- Color contrast transitions in flooring and steps



Fall Prevention Approach

- Safety
 - Motion detection *also helps for wandering prevention
- Prevention
 - Adequate hydration, nutrition, and prevent UTIs
 - Use restroom before bed
 - Maintain scheduled sleep/wake times
 - Distract with activities if anxious and pacing



Fall Prevention Task at Hand

- Exercise and skilled therapy can help to prevent falls
- Integrating regular activity into daily routine
- Limit sitting for extended periods of time



Nutrition and Hydration

- Do NOT ask “Did you eat?” or “Do you want to eat?” or “Are you hungry?”
- Eat together
- Leave out food in sight
- Remove from sight depending on the problem



Medications versus Activities

- Activities are better than medicines for reducing dementia behaviors!
- Tailored Activity Program (Gitlin et al., 2009)
 - Prescribed set of activities for client to perform daily
 - Incorporates caregiver education and training
 - Teach how to simplify, set up environment, and provide appropriate cuing





Activity Engagement

- Make the person feel needed and useful
- Ideally familiar, repetitive in nature
- Try to find activities that are simple and only need caregiver to initiate
- Find activities that bring pleasure = caregiver stress relief
- **It is the doing that counts, not the end result**

Activity Engagement





Dress up, try on Jewelry

Do familiar household tasks
that have meaning



Case Study: Gilbert

- 60 years old, has a DD, lives in a group home.
- Primary caregiver, Jamie
- 'Released' from several day programs because of agitation and aggression.
- Jamie notices shuffling more and arguing more, at night going through his drawers
- No longer seems to want to do the things he used to enjoy helping with
- Jamie's concerns: Home safety (especially steps) and behavior incentives (Cardinals)

What are your thoughts about these behaviors?

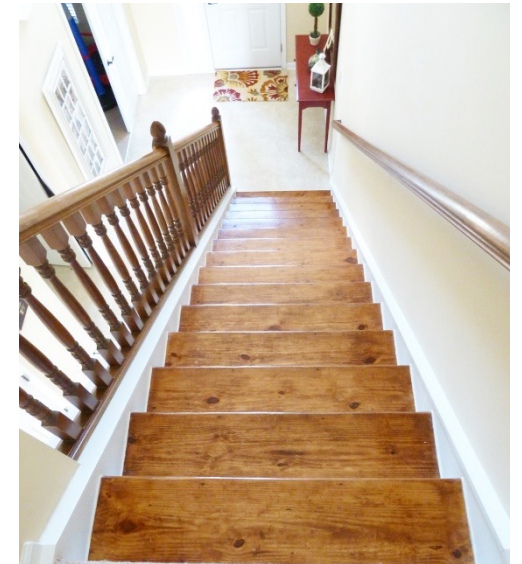
Any ideas for Jamie about what might help with these problems?

Gilbert Revealed

- In & out of hospital several times due to falls and other problems
- Gilbert was diagnosed with: dementia
- The dementia diagnosis helped Jamie decide to try to get more help to learn more about strategies for people with dementia
- Jamie was referred to us at Memory Care Home Solutions

Memory Care Home Solutions & Gilbert

- Home safety
 - Steps: main level versus bilateral rails
 - Motion detectors
- Behavior management
 - Incentives don't work anymore
 - Connection to motivators in the moment instead
- Activities
 - Made laundry simpler – “sock game”
 - Connection to motivators – planning ‘dinner’ and shelling peanuts, etc.!





Questions?

- *Call us! We can help!*
- *(314) 645-6247 or go to our website: <http://www.memorycarehs.org>*

References

- Alzheimer's Association (2018). 2018 Alzheimer's disease facts and figures. Retrieved on 22 March 2018 from https://www.alz.org/documents_custom/2018-facts-and-figures.pdf
- American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*, 68, S1–S48. <https://doi.org/10.5014/ajot.2014.682006>
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., ... Resources for Enhancing Alzheimer's Caregiver Health (REACH) II Investigators. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. *Annals of Internal Medicine*, 145(10), 727–738. [http://doi.org/10.1016/0022-2836\(89\)90001-6](http://doi.org/10.1016/0022-2836(89)90001-6)
- Choi, S., Budhathoki, C., & Gitlin, L. (2017). Co-occurrence and predictors of three commonly occurring behavioral symptoms in dementia: Agitation, aggression, and rejection of care. *The American Journal of Geriatric Psychiatry*, 25(5), 459-468. <http://dx.doi.org/10.1016/j.jagp.2016.10.013>
- Dooley, N. R., & Hinojosa, J. (2004). Improving quality of life for persons with Alzheimer's disease and their family caregivers: brief occupational therapy intervention. *The American Journal of Occupational Therapy*. : Official Publication of the American Occupational Therapy Association, 58, 561–569. <http://doi.org/10.5014/ajot.58.5.561>
- Fauth, E. B., Femia, E. E., & Zarit, S. H. (2016). Resistiveness to care during assistance with activities in daily living in non-institutionalized persons with dementia: Associations with informal caregivers' stress and well-being. *Aging and Mental Health*, 20(9), 888-98. Doi: 10.1080/13607863.2015.1049114.
- Gitlin, L. N., Cigliana, J., Cigliana, K., Pappa, K. (2017). Supporting family caregivers of persons with dementia in the community: Description of the 'Memory Care Home Solutions' Program and its impacts. *Innovation in Aging*, 00(00), 1-13. Doi: 10.1093/geroni/igx013
- Gitlin, L. N., Hodgson, N. (2015). Caregivers as therapeutic agents in dementia care: The evidence-base for interventions supporting their role. In J. Gaugler and R. Kane, (eds), *Family Caregiving in the New Normal* (pp. 305-353). Philadelphia, PA: Elsevier.
- Gitlin, L. N., Hodgson, N. A., & Choi, S. S. W. (2016). Home-Based Interventions Targeting Persons with Dementia: What Is the Evidence and Where Do We Go from Here? In *Dementia Care* (pp. 167–188). Cham: Springer International Publishing. http://doi.org/10.1007/978-3-319-18377-0_11
- Gitlin, L. N., & Rose, K. (2014). Factors Associated with Caregiver Readiness to Use Nonpharmacologic Strategies to Manage Dementia-related Behavioral Symptoms. *International Journal of Geriatric Psychiatry*, 29(1), 93–102. <http://doi.org/10.1002/gps.3979>
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010a). A Biobehavioral Home-Based Intervention and the Well-being of Patients With Dementia and Their Caregivers: The COPE Randomized Trial. *JAMA : The Journal of the American Medical Association*, 304(9), 983–991. <http://doi.org/10.1001/jama.2010.1253>
- Gitlin, L. N., Winter, L., Dennis, M. P., Hodgson, N., & Hauck, W. W. (2010b). Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacological intervention. *Journal of the American Geriatrics Society*, 58(8), 1465-1474. Doi: 10.1111/j.1532-5415.2010.02971.x
- Graff, M. J. L., Vernooij-Dassen, M. J. M., Thijssen, M., Dekker, J., Hoefnagels, W. H. L., & Rikkert, M. G. M. O. (2006). Community based occupational therapy for patients with dementia and their care givers: Randomised controlled trial. *British Medical Journal*, 333 (7580), 1196-. <http://doi.org/10.1136/bmj.39001.688843.BE>
- Hithersay, R., Hamburg S, Knight B, & Strydom A. (2017). Cognitive decline and dementia in Down syndrome. *Current Opinion in Psychiatry* 30.2 102-107. <https://www.ncbi.nlm.nih.gov/labs/articles/28009725/>

References Continued

- Hutchings, B. L., Olsen, R. V., & Moulton, H. J. (2008). Environmental evaluations and modifications to support aging at home with a developmental disability. *Journal of Housing for the Elderly*, 22(4), 286–310. <http://doi.org/10.1080/027638908024>.
- Jensen, L., & Padilla, R. (2017). Effectiveness of environment-based interventions that address behavior, perception, and falls in people with Alzheimer's disease and related disorders: A systematic review. *American Journal of Occupational Therapy*, 65, 532-540. <https://doi.org/10.5014/ajot.2017.027409>
- Kenshole, A., Gallichan, D., Pahl, S., & Clibbens, J. (2017). Lifestyle factors and Alzheimer's disease in people with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*. [Epub ahead of print] <http://dx.doi.org/10.1111/jar.12369>
- Lautarescu, B. A., Holland, A. J., & Zaman, S. H. (2017). The early presentation of dementia in people with Down syndrome: A systematic review of longitudinal studies. *Neuropsychology Review*. 27(1):31-45. <https://doi.org/10.1007/s11065-017-9341-9>
- Levy, L. L., & Burns, T. (2011). The Cognitive Disabilities Reconsidered Model: Rehabilitation of adults with dementia. In N. Katz (Ed.), *Cognition, Occupation, and Participation Across the Lifespan*, (3rd ed., pp. 407-441).
- Lott, I.T., & Dierssen, M. (2010). Cognitive deficits and associated neurological complications in individuals with Down's syndrome. *Lancet Neurol*, 9(6):623-33.
- Marquardt, G., Johnston, D., Black, B. S., Morrison, A., Rosenblatt, A., Lyketsos, C. G., Samus, Q. M. (2011a). Association of the spatial layout of the home and ADL abilities among older adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 26(1), 51-57. <https://doi.org/10.1177/1533317510387584>
- Mukherjee, A., Biswas, A., Roy, A., Biswas, S., Gangopadhyay, G., Das, S. K. (2017). Behavioral and psychological symptoms of dementia: Correlates and impact on caregiver distress. *Dementia and Geriatric Cognitive Disorders*, 7(3), 354-365.
- Naaldenberg, J., Kuijken, N., van Dooren, K., & van Schrojenstein, H. (2013). Topics, methods and challenges in health promotion for people with intellectual disabilities: A structured review of literature. *Research in Developmental Disabilities*, 34, 4534–4545. <http://doi.org/10.1016/j.ridd.2013.09.029>
- National Down Syndrome Society. (n.d.) An Introduction to Alzheimer's. Accessed 2018 May 4 at <<https://www.ndss.org/resources/alzheimers/>>.
- Pimouguet, C., Le Goff, M., Wittwer, J., Dartrigues, J.-F., & Helmer, C. (2017). Benefits of occupational therapy in dementia patients: Findings from a real-world observational study. *Journal of Alzheimer's Disease*, 56, 509-517. doi: 10.3233/JAD-160820.
- Scalen, S. G., & Reisberg, B. (1992). Functional assessment staging (FAST) in Alzheimer's disease: Reliability, validity, and ordinality. *International Psychogeriatrics*, 4(1), 55-69.
- Schaber, P. (2010). Occupational therapy practice guidelines for adults with Alzheimer's disease and related disorders. Bethesda, MD: AOTA Press.
- Smallfield, S., & Heckenlaible, C. (2017). Effectiveness of occupational therapy interventions to enhance occupational performance for adults with Alzheimer's disease and related major neurocognitive disorders: A systematic review. *American Journal of Occupational Therapy*, 71(5), 7015180010. <https://doi.org/10.5014/ajot2017.024752>
- Struckmeyer, L. R. & Pickens, N. D. (2016). Home modifications for people with Alzheimer's disease: A scoping review. *American Journal of Occupational Therapy*, 70(1), 7001270020p1-9. <https://doi.org/10.5014/ajot.2015.016089>
- Zhu, C. W., Scarmeas, N., Ornstein, K., Albert, M., Brandt, J., Blacker, D., ... Stern, Y. (2015). Healthcare use and cost in dementia caregivers: Longitudinal results from the Predictors Caregiver Study. *Alzheimer's & Dementia : The Journal of the Alzheimer's Association*, 11(4), 444–454. <http://doi.org/10.1016/j.jalz.2>
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