



Behavioral and Psychological Symptoms in Dementia Strategies to Identify, Prevent and Mitigate

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CATHOLIC CHARITIES
HAWAI'I
CIRCLE OF CARE FOR DEMENTIA



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Disclosure:

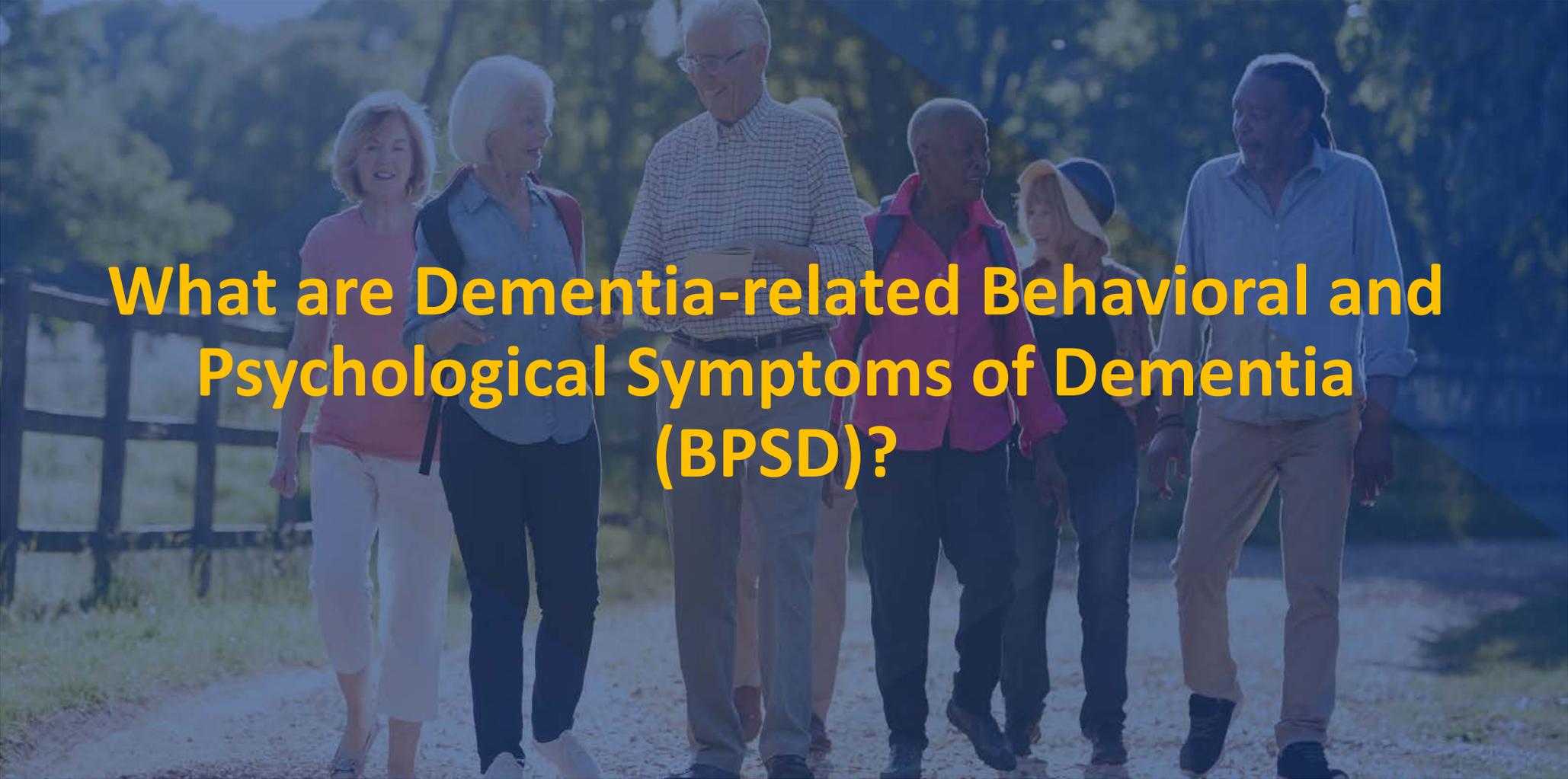
Consultant to various community-based agencies concerning dementia care;
Inventor of an online program for an intervention (Tailored Activity Program) for which Johns Hopkins University, Drexel University, and Dr. Gitlin are entitled to fees. Co-author of a book used in programs for which Dr. Gitlin is entitled to royalties

Objectives

What are dementia-related behavioral and psychological symptoms (BPSD)?

How can BPSD be prevented, reduced or managed?

- DICE Approach
- Tailored Activity Program (TAP)
- WeCareAdvisor Study – enrollment is open



What are Dementia-related Behavioral and Psychological Symptoms of Dementia (BPSD)?



Common Scenarios

- Mother hears mail being delivered and opens door and walks out
- Husband confuses shaving cream with chemical cleaning foam bottle
- Wife wakes up at night and wanders throughout home
- Mother hides things and hordes
- Father is restless and paces
- Mother vocalizes and screams all day from her bed
- Brother refuses needed help bathing
- Husband leaves stove on
- Sister asks the same thing repeatedly
- Husband follows (shadows) wife throughout day



Poll Questions

- Has a health provider asked you or the person you care for about behavioral symptoms?
- Has a health provider ever systematically assessed for behavioral symptoms?
- Have you received from a health provider strategies for managing behavioral symptoms?
- Has any of your health providers asked you if you are caregiving?

Clusters of BPSD

Loss of ability to relate to partner and have empathy, major challenge particularly for people with FTD and their spouses

Rejection of care, Restlessness, & Aggression may occur alone or co-occur, & have different etiologies and hence treatments

'Aggression'

Aggressive resistance
Physical aggression
Verbal aggression

'Agitation'

Wandering
Aimlessly
Trailing
Restlessness
Repetitive actions
Dressing/undressing
Sleep disturbance

'Apathy'

Withdrawn
Lack of interest
Amotivation

'Depression'

Sad
Tearful
Hopeless
Low self-esteem
Anxiety
Guilt

Hallucinations
Delusions
Misidentifications

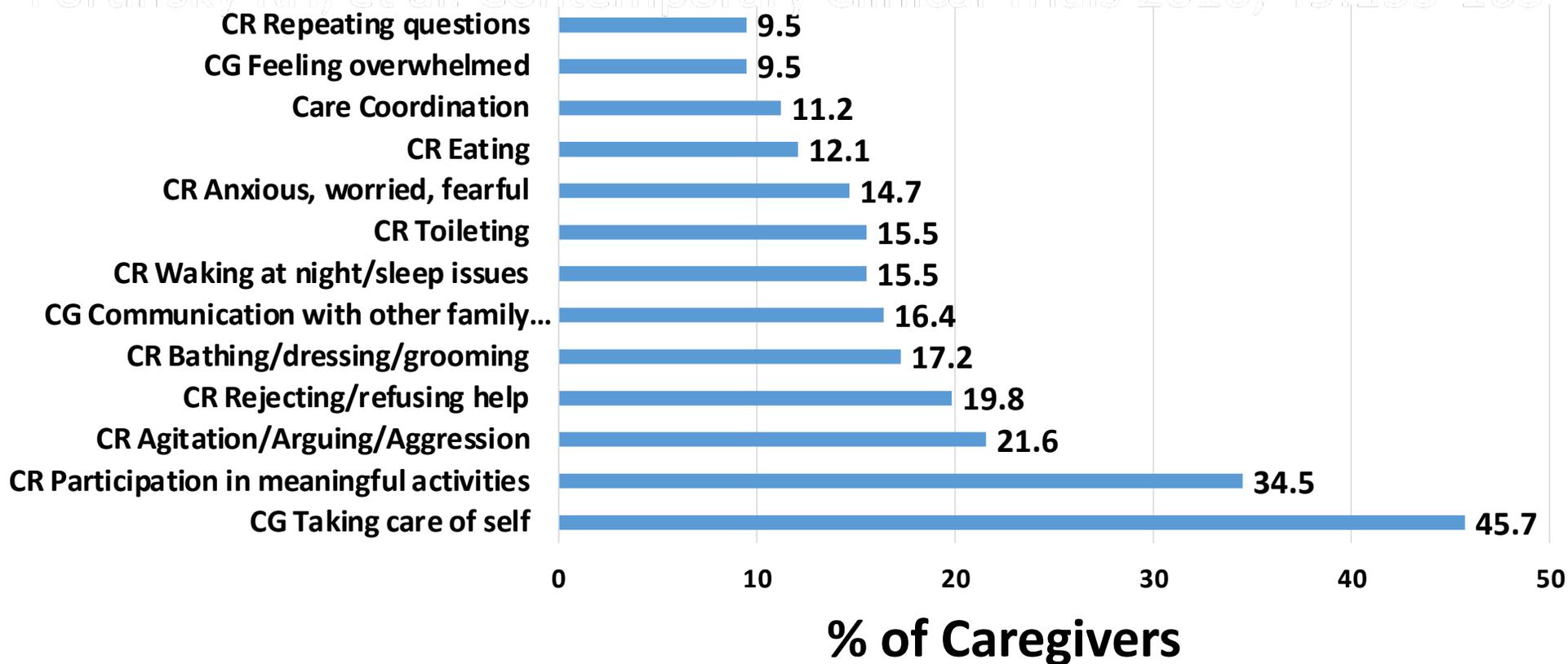
Do not occur as frequently as other behaviors, and may not be upsetting to either individual or family members

Source: Rabheru, 2004

Adapted from McShane R. Int Psychogeriatr 2000; 12(Suppl 1): 147-54

Most Common Challenges by Percent of Caregivers in the COPE Program (N=116)

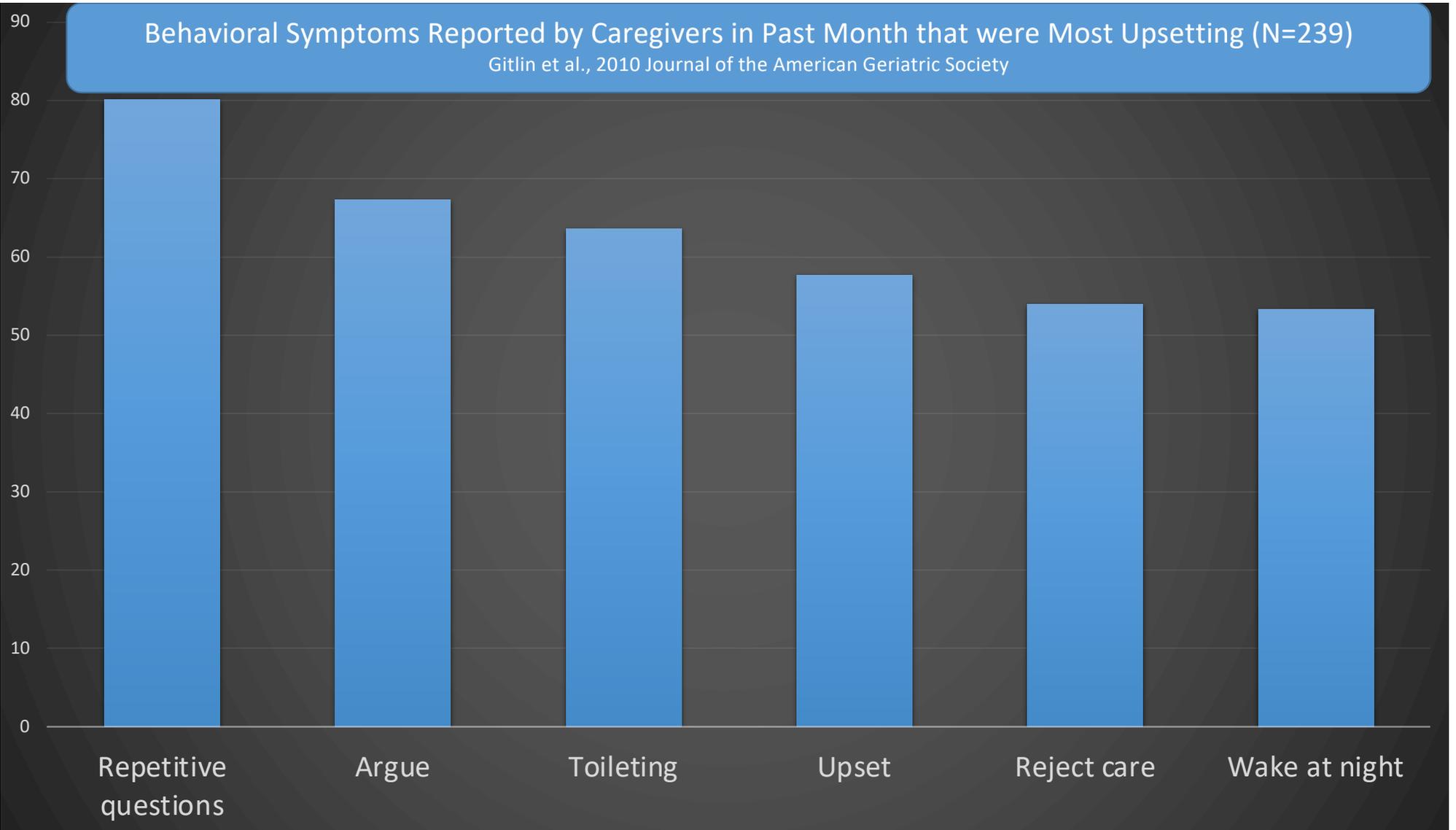
Fortinsky RH, et al. Contemporary Clinical Trials 2016; 49:155-165



Fortinsky RH, et al. Contemporary Clinical Trials 2016; 49:155-165

Behavioral Symptoms Reported by Caregivers in Past Month that were Most Upsetting (N=239)

Gitlin et al., 2010 Journal of the American Geriatric Society



Behaviors Associated with Negative Outcomes

For Person Living with Dementia

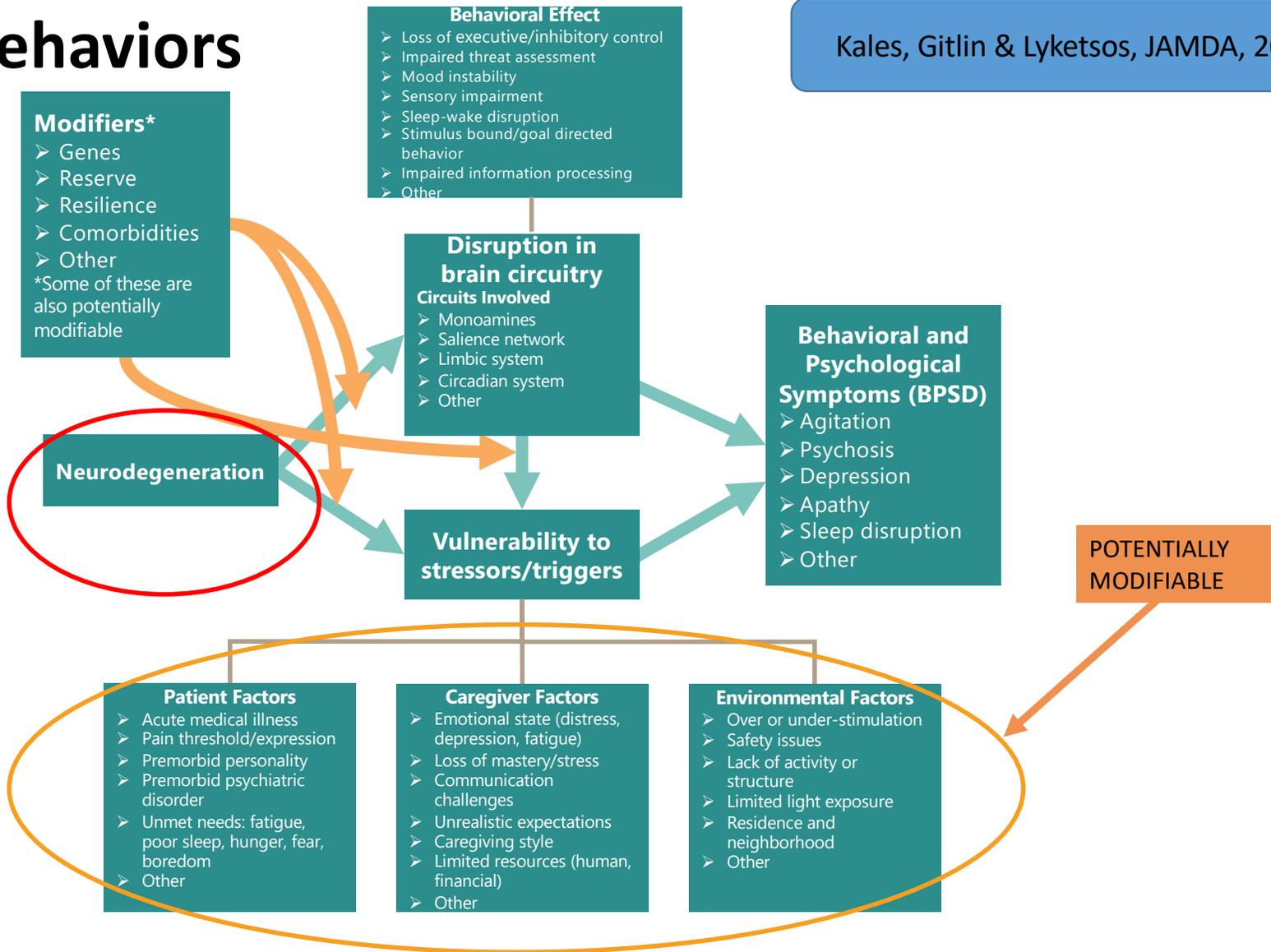
- More rapid decline cognitively
- Increased hospitalizations
- Poorer quality of life
- Distressing to person
- Rejection from care facilities

For Family Caregivers

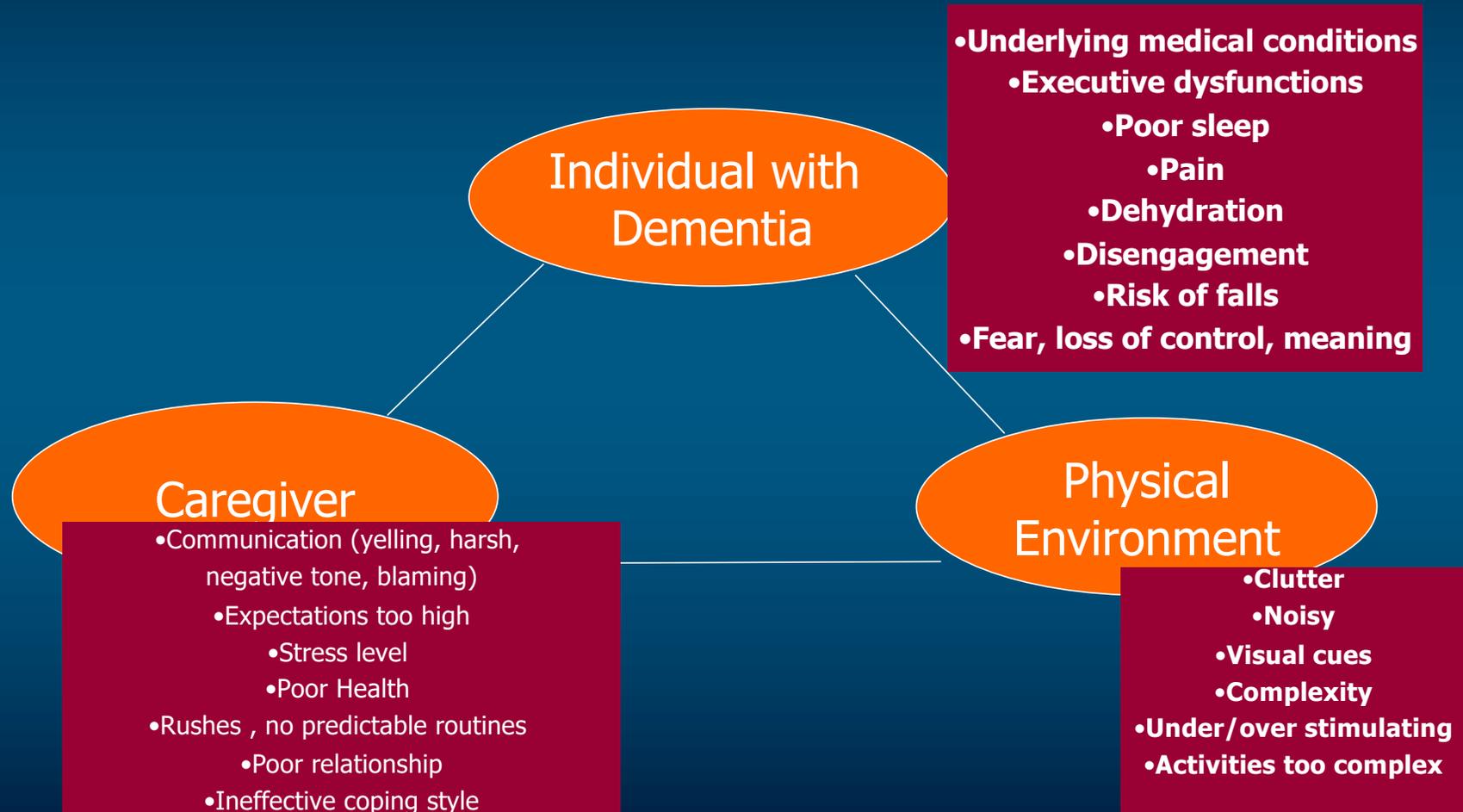
- More time providing care
- Increased depression and distress
- Distressed/upset
- Trigger for residential placement
- Increased care costs

Why do Behaviors occur?

Kales, Gitlin & Lyketsos, JAMDA, 2019



To Address BPSD – Think of a Triangle





How can BPSD be prevented, reduced or managed?



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AgeWell
Collaboratory
College of Nursing and Health Professions



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College of
Nursing and
Health Professions

Current Treatments

- Behavioral and psychological symptoms occur across all disease stages and etiologies
 - Under-detected
 - Under-treated
- Behavioral medications (anti-anxiety, anti-depressants, psychotropics):
 - May have limited utility
 - Can cause more harm than good
 - Do not typically address behaviors of most distress to families
- Medication-free approaches:
 - Directly address behaviors of concern to the family
 - Are low-risk and non-intrusive to families
 - Increase confidence in caregiving ability
 - Are applicable across all disease stages and types of etiologies
- Medication-free approaches are not “one-size-fits-all,” but can be tailored to what is most realistic and helpful to families

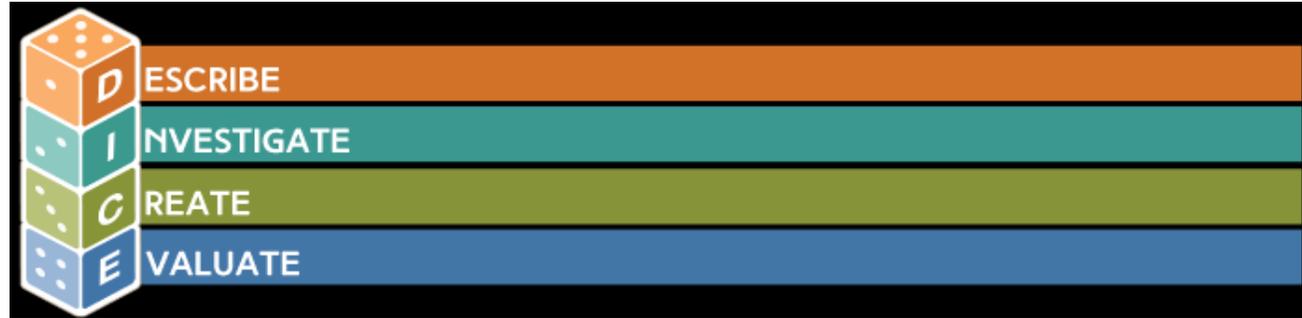


DICE APPROACH

Managing Challenging Behavioral and Psychological Symptoms



<https://diceapproach.com/>



- **Describe** a behavior that challenges; who, what, where, when, and how the behavior occurs
- **Investigate** thinking like a detective and explore the person with dementia, the caregivers, and environment for possible clues to triggers underlying possible causes of behavior
- **Create** a prescription in collaboration with your team to help prevent and manage behaviors
- **Evaluate** and review prescription effectiveness, and modify or restart the process as needed



Describe

Resident (Mrs. J)

- Trying to leave the facility; Blocking door; Screaming and striking out; Escalating aggression with staff intervention

Caregivers

- Worried Mrs J might escape; Concerned about impression of new residents and families at entrance; Worried that Mrs J would fall; Staff concerns about being hurt

Environment

- Noisy music group; Saw front door when she exited; Surrounded by staff and residents as they left concert

Example of DICE APPROACH

Investigate

Resident

- Recent move from another part of building; Due to anxiety, had recent increase in meds; Functional and cognitive fluctuations of Parkinson's; Moderate dementia, poor executive function; History of rape as a teenager
- Rule out acute illness

Caregivers

- Taken off guard by sudden uncooperativeness; did not know her well; Communication style inappropriate; Fear and embarrassment increased their stress and led to physical intervention

Environment

- Over-stimulating; Routine was changed by move; Seeing door gave her a view of outside

DICE con't

Create

Resident:

- Rule out acute medical issues; Decrease SSRI back to original dose; Avoid antipsychotics which could worsen Parkinson's; Consider ways to decrease anxiety (e.g. music, exercise); Use of 4-wheeled walker for stability

Caregivers

- Identify less overstimulating activities; Use simple calm communications; Avoid evoking memories of sexual assault; Inform and explain any need for touch or direction; Educate staff about her history; If tries to leave event, walk with her, calmly redirect her back into facility when less agitated

Environment

- Create routines that are safe, not overstimulating and meaningful; using signage to redirect and cue

Evaluate

Resident:

- Monitor behavior change once SSRI is decreased; Evaluate effect of each strategy; Monitor anxiety levels

Caregivers

- What approaches did staff try? Were there any that they were resistant to? If so, why?; What worked? What didn't?; Any unintended consequences or "side effects" noted?

Environment

- What changes were made? Were new routines instituted? Any issues with that?



Mrs. B Lives with Daughter in her Apartment



Describe

Mrs. B

- Sits in chair all day
- Uses commode every 15 minutes
- Has nothing to do

Daughter

- Withholds liquids due to frequent urination
- Concern about mom's quality of life
- Worried mom will fall

Environment

- Commode in visual field
- Nothing interesting in environment
- Noisy music plays all day

Investigate

Mrs. B

- Rule out UTI, medication changes
- Assess skin integrity
- Identify abilities
- Determine fall risk level
- Identify activities of interest now/past

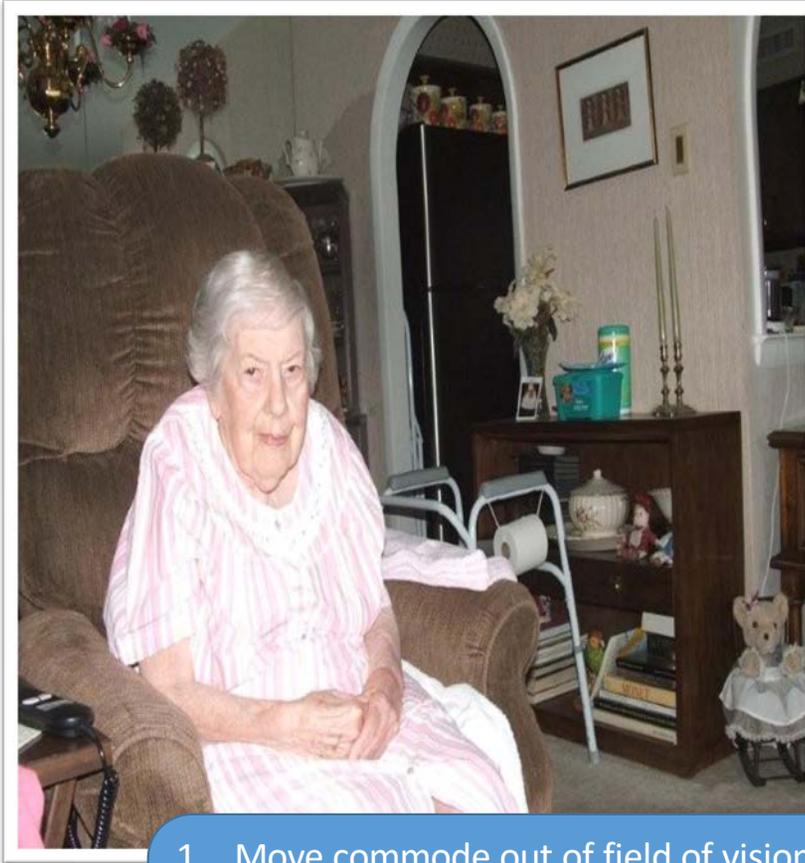
Daughter

- Overestimates what mom can do
- Unclear communications

Environment

- Mrs. B only sees commode
- Has nothing to do or see of visual interest

Create and Evaluate



1. Move commode out of field of vision but close by due to fall risk
2. Put mom on toileting schedule
3. Keep mom hydrated throughout day (limit coffee/tea after morning)
4. Instruct caregiver how to set up activities and cue, establish daily routines
5. Introduce table-top gardening, flower arranging as high valued activities for mom

Tailored Activity Program (TAP)

An evidence-based program that improves quality of life of people living with dementia and their caregivers.

It uses activities tailored to **abilities** and **interests** of people living with dementia, instructs caregivers in setting up and using activities, and provides disease education and stress reduction techniques.



Tailored Activity Program (TAP) is Local and Global



TAP
ADAPTED
FOR AND
TESTED IN
Different
SETTINGS
and around
the World

Hospitals



Adult Day Services

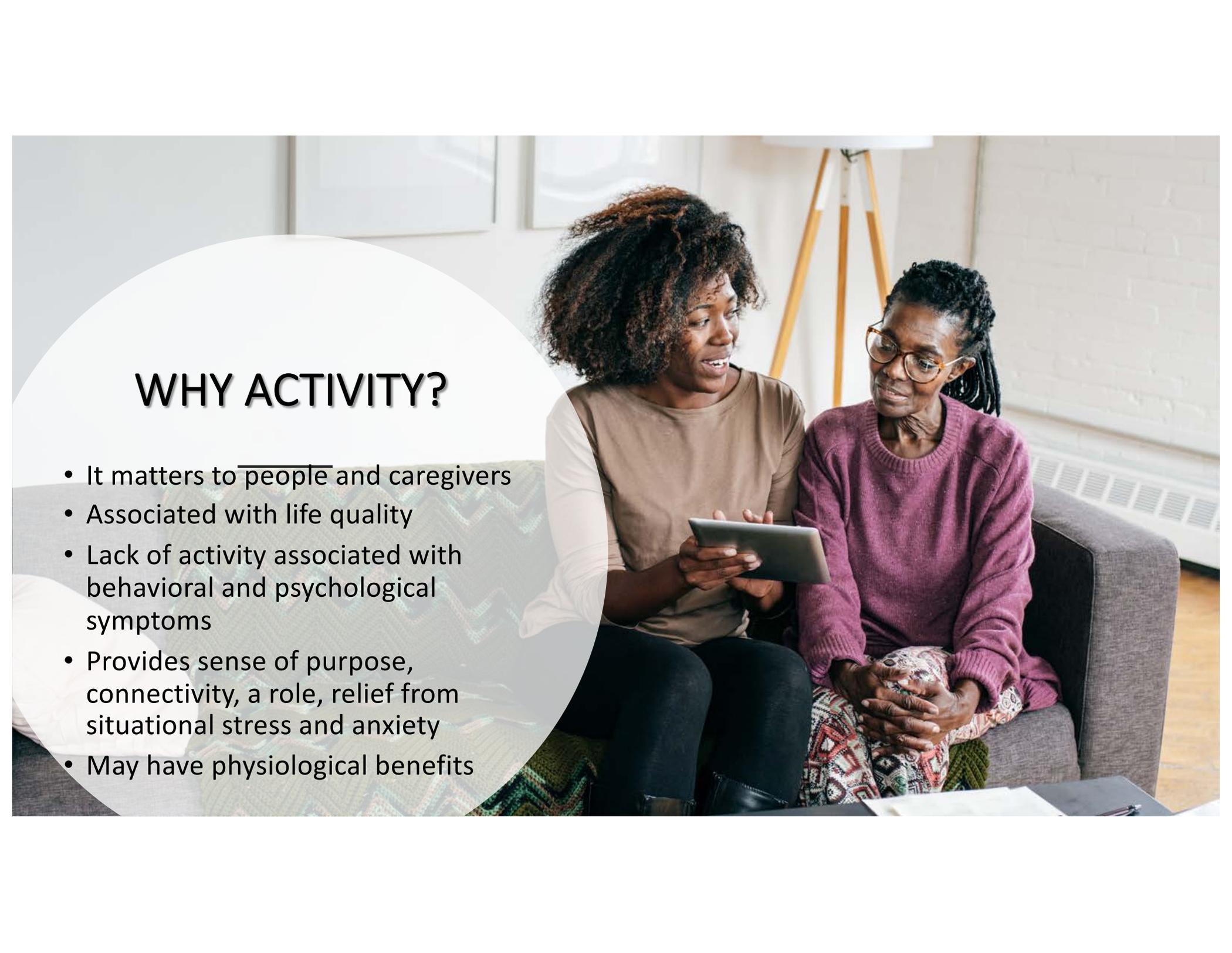


Homes



Residential Facilities

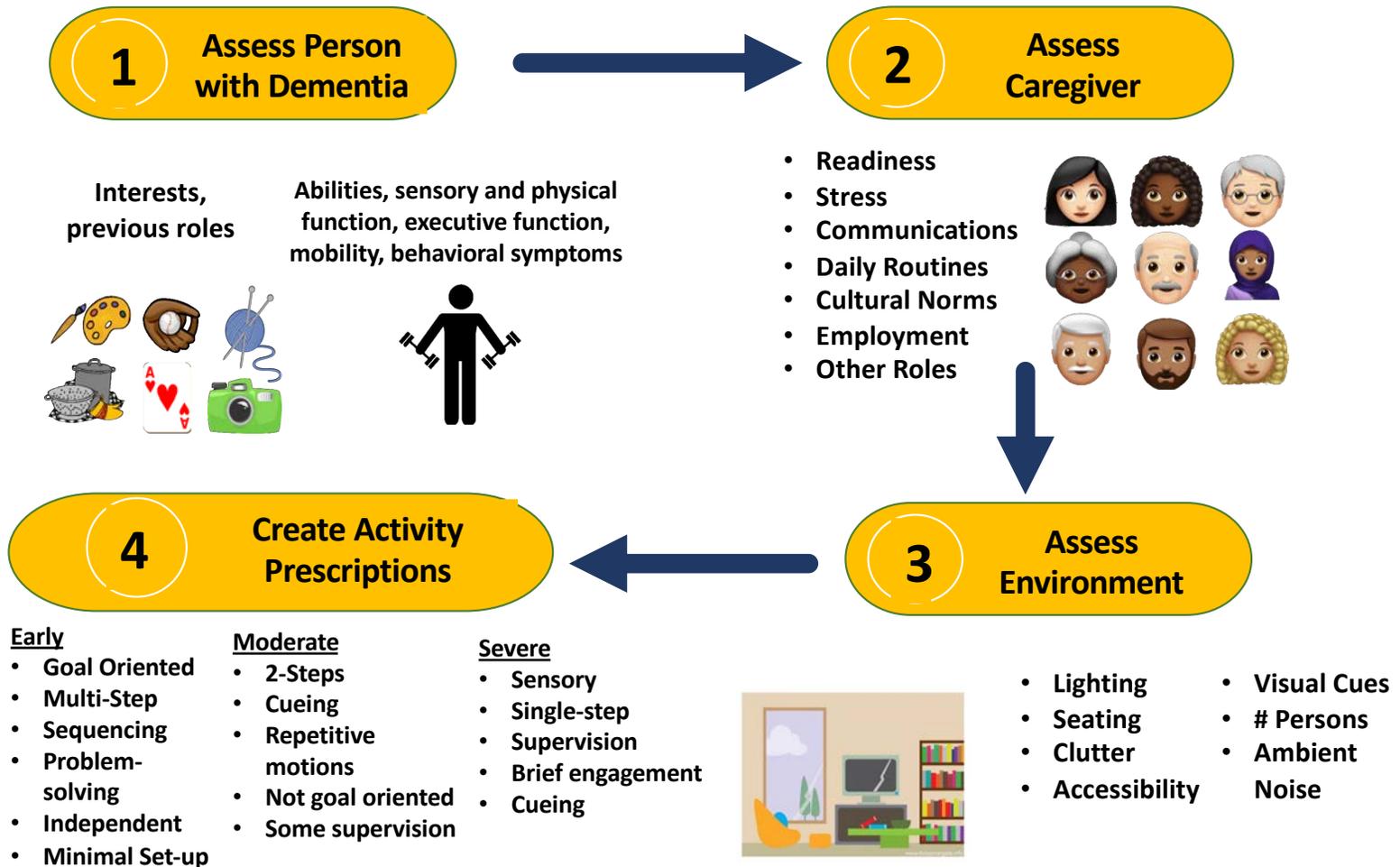


A photograph of two Black women sitting on a grey couch in a modern living room. The woman on the left, with curly hair and wearing a beige top, is holding a tablet and looking at it. The woman on the right, wearing glasses and a purple sweater, is looking at the tablet with interest. The background shows a white brick wall, a wooden tripod lamp, and a window with blinds. A large white circle is overlaid on the left side of the image, containing text.

WHY ACTIVITY?

- It matters to people and caregivers
- Associated with life quality
- Lack of activity associated with behavioral and psychological symptoms
- Provides sense of purpose, connectivity, a role, relief from situational stress and anxiety
- May have physiological benefits

Phase I of TAP



Phase II = Instruct Caregivers in Use of Activities

Caregiver learns person's capabilities, relaxing the rules, cueing and how to set up and monitor activity



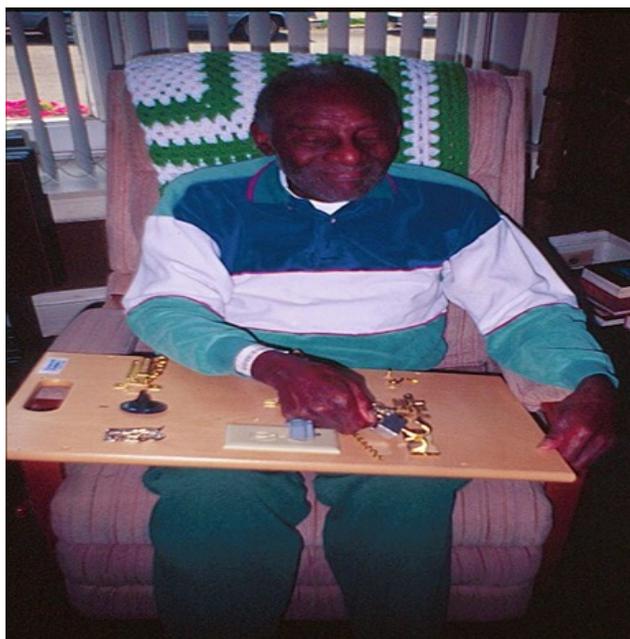
Caregiver learns stress reduction techniques, tries activities & adjustments made if necessary



Phase III = Generalization

Caregiver learns to modify activities for future declines and how to use strategies (communication, simplification) for other care challenges

Examples of Activities





For Persons Living with Dementia

Reduced behavioral symptoms

Reduced physical dependence

Fewer health events

Improved quality of life

For Caregivers

Improved Caregiver confidence

Improved caregiver wellbeing

More time for self

And for Health Systems, cost savings

Select sources: Gitlin et al., under review; Gitlin et al., 2008; 2010; 2014; 2017; Novieli et al., 2018; O'Connor et al., 2017)



A web-based application to assist the family caregiver to assess, manage and track behavioral symptoms and potential modifiable contributing factors, and provide tailored strategies for in-home, non-pharmacologic behavior management





- Peer navigator
- DICE approach
 - WeCareAdvisor Prescription
- Caregiver Survival Guide
- Daily caregiver tips
- Frequent Reminder Prompts (randomized)
 - Low intensity: weekly emails
 - High intensity: weekly emails + phone calls from research assistant

Information we used to create this prescription



When I was dealing with apathy, I found this information helpful:

People with dementia may have difficulties identifying, planning, organizing, or initiating an activity or task. This may contribute to what appears to be apathy. (880)

For Health & Safety



Like you, I wasn't too worried that the behavior was a safety concern. But it's still important to make sure that you and Jacob stay safe. These tips can help you understand more about Jacob's behavior.

- Make sure Jacob is safe and does not have access to anything that could cause harm to himself or others. (985)
- You have indicated that Jacob has a chronic medical condition and that it may have worsened around the same time the behavior appeared. Please check with Jacob's doctor to see if the behavior could have been triggered by the medical problem changing or getting worse. Treating the medical problem may alleviate the behavior. (986)
- Non-drug therapies can be used to help alleviate mild pain including massage, application of head or cold packs, gentle exercise and stretching and using relaxation techniques (such as listening to music or deep breathing). (992)

For Jacob



These tips should help make things easier for Jacob and keep him involved in appropriate activities. If you have questions, add them [My Notes](#) so you can remember to ask your health care provider.

- Try activities that do not require Jacob's active participation, such as listening to his favorite music. (212)
- Allow Jacob enough time to complete an activity. (215)

Other key features of WeCareAdvisor

Can be accessed from any device (smartphone, iPad, tablet, computer) at any time of day or night when caregiver wants

Up to date content in the Caregiver Survival Guide Section

- Use of activities
- Preparedness and COVID-19
- Stigma
- Talking to a healthcare provider from a different cultural/race/ethnic background

Voice activation for specific sections

Daily tips cover topics on safety, taking care of self, tips for managing dementia-related behaviors

Testing of different prompts to evaluate approaches supporting a “habit” of using WeCareAdvisor when needed

How Other Caregivers Use DICE




I find it helpful to hear from other caregivers. It reminds me that there are other people dealing with similar problems, and I often get good suggestions from them. Below, you can read the stories of some caregivers who have used WeCareAdvisor.

Tap on a Caregiver to read their story...



Linda deals with her husband's sleep problems



Teresa learns how to reduce her aunt's agitation



Patricia learns how to keep her mom engaged in activities



Eric is frustrated by his mother's repeated questions



William helps his wife with anxiety



Anita's dad wants to "go home"



Alan's father struggles with self-care



Jennifer learns how to manage her wife's changes in appetite and eating



David copes with his wife's delusions



Michael helps manage his friend's motor disturbances



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Describe - Apathy



Now it's time to Describe the behavior of Georgia.

First, tell WeCareAdvisor how frequently the behavior occurs and how severe the behavior is. Later, you'll answer the same questions to see if there's been any change.

(Question 2 of 13) Please tell us how frequently this behavior is occurring.

- Rarely (less than once per week)
- Sometimes (about once per week)
- Often (several times per week but less than every day)
- Very often (once or more per day or continuously present)

(Question 3 of 13) Please rate how severe the behavior is. By severe we mean is the behavior intense or extremely unpleasant to Georgia?

- Mild (present but harmless and produces little distress)
- Moderate (distressing and disruptive)
- Severe (very disruptive and a major source of behavioral disruption)

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Investigate - Apathy



Now it's time to "play detective" and Investigate. Think about what else might be going on with Georgia, with you, or with the home environment. I've found this helps me understand why the behavior might be happening. Select any items from the list below that apply to Georgia.

(Question 8 of 13) Select items from the list that apply to the behavior of Georgia. If none of these apply, just click or tap Continue

- Difficulty actively participating in activities
- Frustrated by not being able to do things as before
- Rejects care
- Seems depressed, sad or cries easily
- Lack of activities or daily routine
- Feels overwhelmed

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These tips should help make things easier for Georgia and keep her involved in appropriate activities. If you have questions, add them My Notes so you can remember to ask your health care provider.

Apathy

June 8, 2022



For Georgia

EMAIL

PRINT

- Try activities that do not require Georgia's active participation, such as listening to her favorite music.
- Allow Georgia enough time to complete an activity.

Thanks for answering those questions. Your DICE prescription is below and has tips that were chosen to fit your situation.

Try these tips for about a week to help prevent and manage Georgia's behavior. You may need to try something a few times before you notice a change. Next week you'll answer the same questions about the behavior to see if there's been any improvement.

If you have any questions, you can add them to My Notes to discuss later with your health care provider.

HOW WE CREATED THIS PRESCRIPTION



When I was dealing with apathy, I found this information helpful:



It's nice when we can deal with behaviors without getting upset, but it's definitely stressful to be a Caregiver.

Try these tips to see if they help make things better for both you and Georgia.

For You

- Accept help from others when they offer it.
- Praise Georgia for what she has achieved rather than criticizing her if she stops an activity early.



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Evaluate - Apathy

Now it's time to Describe the behavior of Georgia.

First, tell WeCareAdvisor how frequently the behavior occurs and how severe the behavior is. Later, you'll answer the same questions to see if there's been any change.

Please tell us how frequently this behavior is occurring.

- Rarely (less than once per week)
- Sometimes (about once per week)
- Often (several times per week but less than every day)
- Very often (once or more per day or continuously present)

Please rate how severe the behavior is. By severe we mean is the behavior intense or extremely unpleasant to Georgia?

- Mild (present but harmless and produces little distress)
- Moderate (distressing and disruptive)
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Daily Tips



Hi, Frida. This page has a record of all the daily tips you've received since you started using WeCareAdvisor.

EMAIL

PRINT

Jun. 8, 2022

Faced with a challenging behavior? Try to determine the cause by turning down the television, turning on the lights, using simple, clear instructions.

Jun. 7, 2022

WeCareAdvisor -- Eating healthy foods can reduce stress. Pick up some frozen vegetables and cook in the microwave for a quick side dish.

Jun. 6, 2022

Finding the bathroom may become difficult or disorienting for Georgia. Try keeping all doors shut and/or locked, except for the bathroom.

Jun. 5, 2022

Asking the same question over and over may be caused by boredom and needing something to do. Engage Georgia in an activity like looking at pictures.

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Caregiver Survival Guide

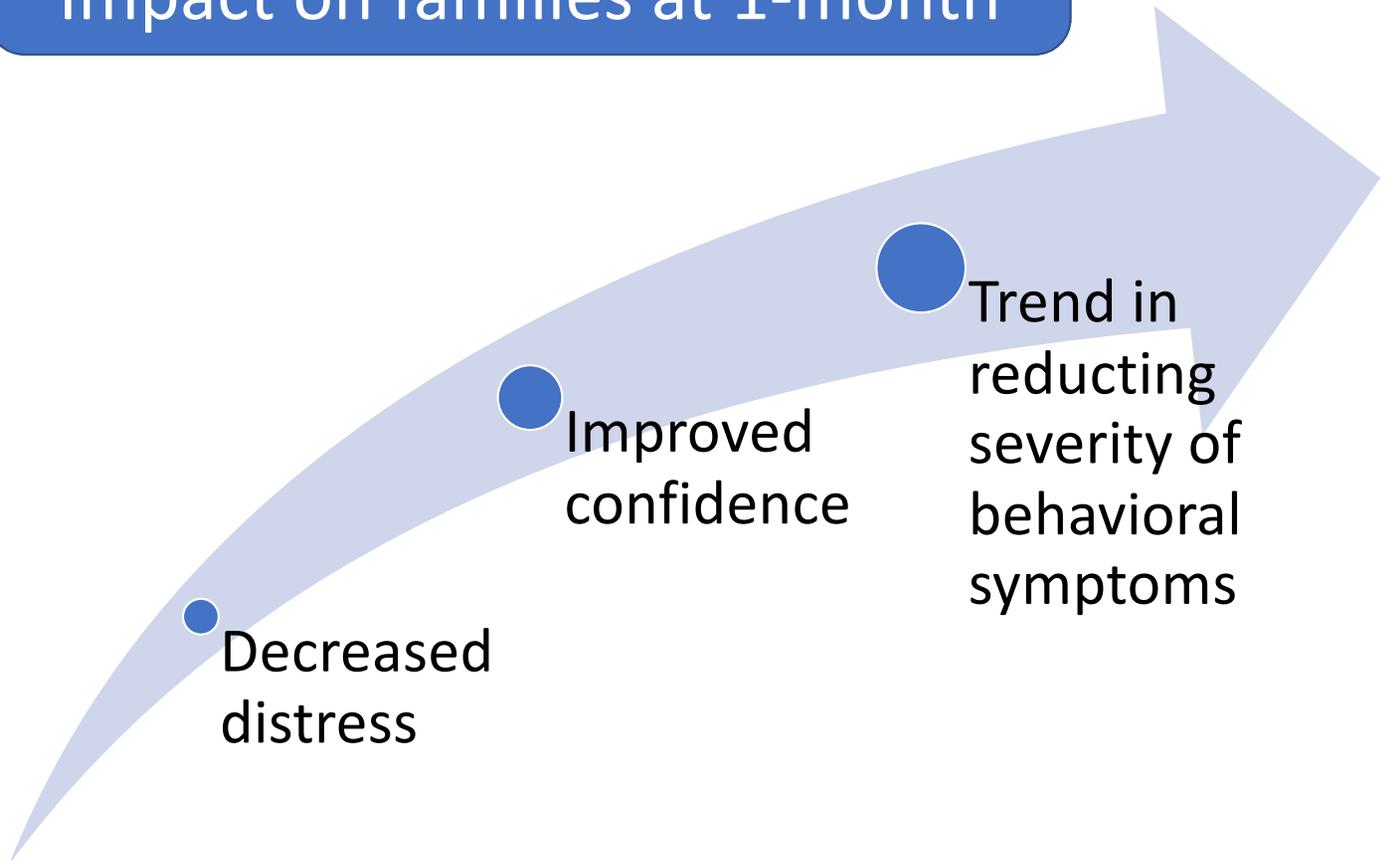


Welcome to the Caregiver Survival Guide. This section has answers to frequently asked questions about dementia and caregiving. If you think of any questions or want to take notes as you're reading, you can add them to My Notes.

Click and learn about each topic to explore the effects of Dementia

- 1. What is dementia? 
- 2. Behaviors in dementia 
- 3. Keeping a person with dementia healthy 
- 4. Helping the person living with dementia engage in activities 
- 5. Common medical considerations in caring for a person living with dementia 
- 6. Impact of COVID-19 
- 7. Keeping a person with dementia safe 
- 8. Addressing Stigma 
- 9. Caring for the caregiver 
- 10. What is your style? 
- 11. Communicating with the health care team 
- 12. Financial issues 
- Glossary 
- References 

Pilot Study (N=57) Impact on families at 1-month



Decreased
distress

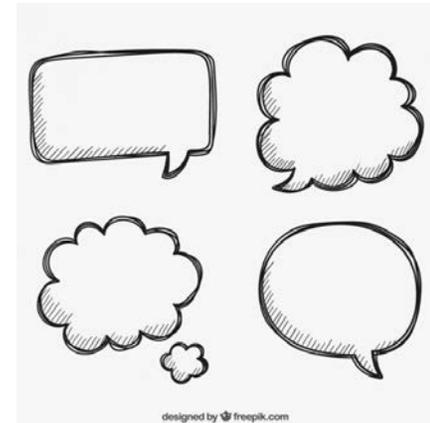
Improved
confidence

Trend in
reducing
severity of
behavioral
symptoms

Kales, H. C., Gitlin, L. N., Stanislawski, B., Myra Kim, H., Marx, K., Turnwald, M., Chiang, C. & Lyketsos, C. G. (2018). Effect of the WeCareAdvisor™ on family caregiver outcomes in dementia: a pilot randomized controlled trial. *BMC Geriatrics*18(113).

What Caregivers Say!

- “Wonderful new tool in my caregiving arsenal”
- “DICE structures my thinking”
- “Survival guide is comprehensive”
- “I shared the tool with my support group and everyone was impressed by the content and ease of use”
- “Love the feeling of support”
- “Ease of use very nice”
- “Daily tips are awesome”
- “I wish I would have had this a long time ago”
- “I learned a great deal more about dementia and the skills to use in dealing with related behaviors”
- “This week PWD had a UTI and the WeCareAdvisor helped to trigger in my mind that something was wrong and he should see the doctor
- “We can go to the doctor, go to support groups, but I see the value of having this daily. This is advice every day.

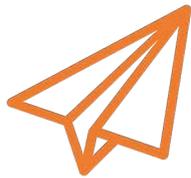


Eligibility Criteria:

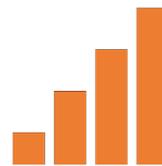
- Primary caregiver is family member (relative, neighbor, fictive kin) to a person diagnosed with dementia for ≥ 6 months
- Report managing >1 behavioral symptom(s) in past month
- Live in the community (not long-term-care)
- Have an email address
- Are 21 years or older
- English-speaking
- Own and use an internet-capable device (e.g. smart phone, computer, tablet, etc.)



Interested in Joining or Learning More?



Email:
WeCare@drexel.edu



Call: 267-359-1111



Visit
WeCareAdvisorStudy.com

Lessons Learned



Behavioral symptoms can be prevented and managed



It involves a problem-solving approach – considering factors associated with the person living with dementia, the caregiver(s) and the living environment



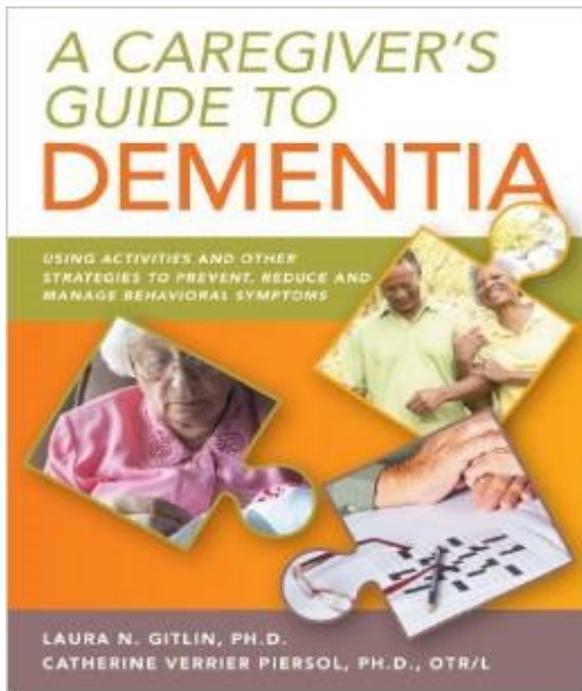
A strategy effective for one family may not be acceptable or helpful to another



Need to adapt a trial and error and systematic problem solving approach to identify and then try strategies

Resources for Families and Health Providers

“Sometimes you just need a checklist.” (Washington Post)



https://www.amazon.com/Caregivers-Guide-Dementia-Activities-Strategies/dp/1933822902/ref=sr_1_1?s=books&ie=UTF8&qid=1454599837&sr=1-1&keywords=gitlin+and+piersol

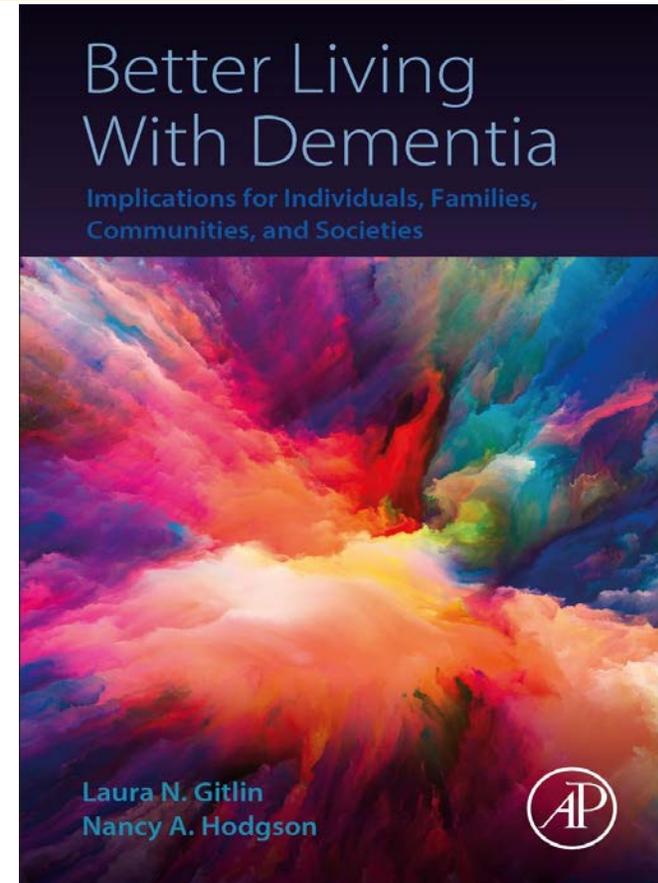
Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies
Massive Open Online Course (MOOC)



Drs. Nancy Hodgson and Laura Gitlin lead the MOOC, an international educational forum for health professionals, students, family caregivers, and anyone affected by dementia.

ON DEMAND

SIGN UP TODAY! www.coursera.org/course/dementiacare



<https://www.amazon.com/Better-Living-Dementia-Implications-Individuals-ebook/dp/B07DLRQY4G>

Questions and Discussion

